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Shoulder impairment in persons with a spinal cord injury & associations with activities and participation

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Inge Eriks-Hoogland

SHOULDER IMPAIRMENT

in persons
with a

**spinal cord
injury**

& associations
with

activities and
participation

The studies reported in chapters 2, 3, 4 and 5 of this thesis are part of the research program: “Functional strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of persons with spinal cord injury”. Study 1 reports of a project performed in a collaboration between the Swiss Paraplegic Research and the Swiss Paraplegic Centre.

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 groningen**

Shoulder impairment in persons with a spinal cord injury & associations with activities and participation

PhD Thesis

to obtain the degree of PhD at the
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on the authority of the
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and in accordance with
the decision by the College of Deans.

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Monday 8 September 2014 at 12.45 hours

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The pessimist complains about the wind.

The optimist expects it to change.

The realist adjusts the sail.

William A Ward

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Chapter 1

Introduction



“Healthy ageing is a lifelong process that starts even before conception, with parents who pass on their genes and with them the risks and opportunities for a healthy life course, or the occurrence of illness later in life. Lifestyle, food patterns and environmental factors influence the development of health.

The challenge is Healthy Ageing: growing older in a healthy and active way. Maintaining good health well beyond pension age would greatly enhance quality of life and well-being, as well as labour participation, informal care capacity and other significant contributions to society. However, new knowledge is required about the influence of these factors, and how they interact with one another.”

(Quote: Healthy Ageing Campus Netherlands at <http://www.healthyageingcampus.nl/about/healthy-ageing>)

Subject of this thesis is one of the dominant health issues in persons with a spinal cord injury (SCI): shoulder pain and limitations in shoulder range of motion (ROM) and its consequences on performance of activities and participation.

For many persons with SCI hand-rim wheelchair propulsion becomes their main mode of mobility. Wheelchair propulsion, but also overhead activities, transfers, weight-reliefs and the consequential lack for the shoulder complex to recover from those straining tasks may lead to ‘overuse’ injury in the shoulder complex, resulting in shoulder pain and limitations in shoulder ROM. Shoulder pain and limitations in shoulder ROM might negatively affect activities, participation and quality of life (QOL).

This thesis adds to the understanding of impairment of the shoulder complex in persons with a SCI, that is needed for the development of interventions to preserve or restore shoulder health in persons with SCI, which is a necessity for ‘healthy ageing’ i.e. growing older in a healthy and active way.

After a short description of the health condition SCI, its epidemiology will be presented. Second, an overview of the most important secondary health conditions (SHC) in persons with SCI is presented. Third, the consequences of an SCI on functioning will be explained, introducing the bio-psychosocial model of the International Classification of Functioning, Disability and Health (ICF).¹ Fourth, a description of the functional anatomy of the shoulder complex, the current understanding of shoulder impairment in persons with a SCI and the association of shoulder pain and shoulder ROM with activities and participation in SCI will be described using the ICF as a framework. Fifth, a short description of medical and rehabilitation care in the Netherlands and Switzerland is given. Sixth, the research context

of this thesis is described, giving a brief description of the Dutch prospective cohort study 'Restoration of mobility in spinal cord injury rehabilitation', also called the Umbrella project, and its follow-up study the 'SPinal cord Injury Quality of life Evaluation (SPIQUE)' project, the Swiss Paraplegic Research (SPF) and the Swiss Paraplegic Centre. Finally, an outline with research objectives and research questions of this thesis on shoulder problems in persons with SCI will be presented.

ANATOMY OF THE VERTEBRAL COLUMN, THORAX & SPINAL CORD

The human vertebral column usually consists of 33 vertebrae, of which nine are fused vertebrae in the sacrum and the coccyx. The upper regions comprise the remaining 24, and are grouped under the names cervical (7 vertebrae), thoracic (12 vertebrae) and lumbar (5 vertebrae). The twelve thoracic vertebrae and the dorsal parts of the ribs form the posterior surface of the thorax. The ventral surface is formed by the sternum and costal cartilages. Besides containing and protecting the principal organs of respiration and circulation the thorax is also important a gliding plane for the scapula, part of the shoulder complex.

The vertebral column houses and protects the spinal cord in its spinal canal. The spinal cord is a long, cylindrical fragile structure in the vertebral column that is continuous with the medulla rostrally and ends at the rostral border of the secondary lumbar vertebra. At the caudal end, the spinal cord is cone shaped and is known as the conus medullaris. A filament extending from the conus medullaris is called the filum terminale and is surrounded by lumbosacral nerve roots to form a cluster, the cauda equina. The spinal cord is divided into 31 different segments. Thirty-one pairs of nerves emerge from the spinal cord. At each level of the spinal cord, nerves exit through the intervertebral foramina of the spinal column, caudal to the vertebra of the same name. In the cervical region however, nerves exit through the foramina just rostral to the vertebra of the same name (Figure 1.1).

The spinal cord is essential for the communication between the brain and the periphery, the transmission of sensory information to the brain, and for the regulation of motor and autonomic function. The spinal cord receives information from visceral and somatic receptors through the dorsal roots and transmits this information to higher brain structures (ascending tracts). It receives signals from higher centers through descending tracts and transmits these signals to somatic and visceral target sites through the ventral roots.²

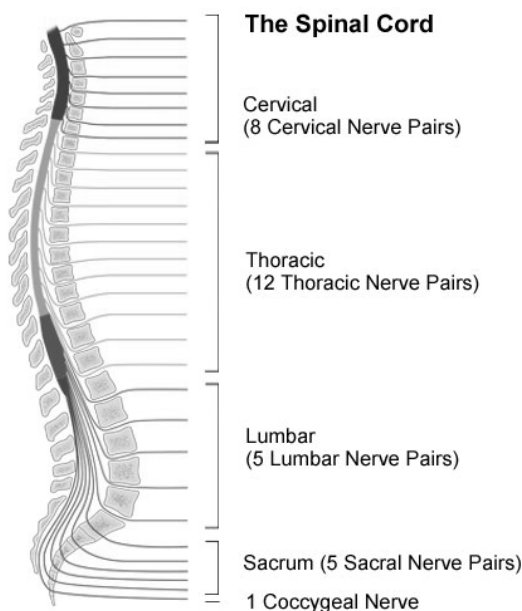


Figure 1.1 Schematic overview of the spinal cord and its emerging nerves (from <http://www.yalemedicalgroup.org/>; Publication permitted).

SPINAL CORD LESION

Due to trauma or health disorders in the spinal column the spinal cord may become damaged, leading to a spinal cord lesion. A spinal cord lesion, also referred to as spinal cord injury (SCI), is an interruption of the neural pathways resulting in muscle weakness or paralysis, loss of sensation and loss of autonomic function below the level of the lesion.²

³ Depending on the level and completeness of the lesion, loss of motor function leads to problems with hand and arm functions, stability of the trunk and mobility of the lower limbs, varying from minor muscle power loss to complete paralysis.² Besides loss of sensory and motor function, loss of autonomic function due to SCI is followed by disturbance of heart function, blood pressure regulation, bladder function, bowel function and sexual function.^{2,3}

Severity of SCI is defined by the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI).⁴ It identifies sensory and motor levels indicative of the most rostral spinal levels demonstrating 'unimpaired' function. Twenty-eight dermatomes are assessed bilaterally using pinprick and light touch sensation and 10 key muscles are assessed

ASIA INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY (ISNCSCI)

Patient Name _____ Date/Time of Exam _____
 Examiner Name _____ Signature _____

RIGHT

MOTOR KEY MUSCLES

UER (Upper Extremity Right)

Elbow flexors C5
 Wrist extensors C6
 Elbow extensors C7
 Finger flexors C8
 Finger abductors (little finger) T1

LER (Lower Extremity Right)

Hip flexors L2
 Knee extensors L3
 Ankle dorsiflexors L4
 Long toe extensors L5
 Ankle plantar flexors S1

(VAC) Voluntary anal contraction (Yes/No) ☐

RIGHT TOTALS (MAXIMUM) (50) (50) (50)

SENSORY KEY SENSORY POINTS

Light Touch (LTR) Pin Prick (PPR)

*** Key Sensory Points**

LEFT

MOTOR KEY MUSCLES

UEL (Upper Extremity Left)

Elbow flexors C5
 Wrist extensors C6
 Elbow extensors C7
 Finger flexors C8
 Finger abductors (little finger) T1

LEL (Lower Extremity Left)

Hip flexors L2
 Knee extensors L3
 Ankle dorsiflexors L4
 Long toe extensors L5
 Ankle plantar flexors S1

(BAP) Deep anal pressure (Yes/No) ☐

LEFT TOTALS (MAXIMUM) (50) (50) (50)

MOTOR SUBSCORES

UER ☐ + UEL ☐ = UEMS TOTAL ☐ (50)

LER ☐ + LEL ☐ = LEMS TOTAL ☐ (50)

MAX (25) (25) (50)

SENSORY SUBSCORES

LTR ☐ + LTL ☐ = LTR TOTAL ☐ (56)

PPR ☐ + PPL ☐ = PPR TOTAL ☐ (56)

MAX (56) (56) (112)

4. COMPLETE OR INCOMPLETE?

Incomplete = Any sensory or motor function in S4-5 ☐

5. ASIA IMPAIRMENT SCALE (AIS) ☐

This form may be copied freely but should not be altered without permission from the American Spinal Injury Association. REV 6/13

Muscle Function Grading

- 0 = total paralysis
- 1 = palpable or visible contraction
- 2 = active movement, full range of motion (ROM) with gravity eliminated
- 3 = active movement, full ROM against gravity and moderate resistance in a muscle specific position
- 4 = active movement, full ROM against gravity and full resistance in a functional muscle position expected from an otherwise unimpaired person
- 5* = (normal) active movement, full ROM against gravity and sufficient resistance to be considered normal (identified inhibiting factors (i.e. pain, disease) were not present)
- NT = not testable (i.e. due to immobilization, severe pain such that the patient cannot be graded, amputation of limb, or contracture of > 50% of the normal range of motion)

Sensory Grading

- 0 = Absent
- 1 = Altered, either decreased/impaired sensation or hypersensitivity
- 2 = Normal
- NT = Not testable

Non Key Muscle Functions (optional)

May be used to assign a motor level to differentiate AIS B vs. C

Movement	Root level
Shoulder: Flexion, extension, abduction, adduction, internal and external rotation	C5
Elbow: Flexion	C6
Wrist: Flexion	C6
Finger: Flexion at proximal joint, extension	C7
Thumb: Flexion, extension and abduction in plane of thumb	C7
Finger: Flexion at MCP joint	C8
Thumb: Opposition, adduction and abduction perpendicular to palm	C8
Finger: Abduction of the index finger	T1
Hip: Adduction	L2
Hip: External rotation	L3
Hip: Extension, abduction, internal rotation	L4
Knee: Flexion	L4
Ankle: Inversion and eversion	L5
Toe: MP and IP extension	L5
Hallux and Toe: DP and PP flexion and abduction	S1
Hallux: Adduction	S1

ASIA Impairment Scale (AIS)

A = Complete. No sensory or motor function is preserved in the sacral segments S4-S5.

B = Sensory incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5 (light touch or pin prick at S4-S5 or deep anal pressure) AND no motor function is preserved more than three levels below the motor level on either side of the body.

C = Motor incomplete. Motor function is preserved below the neurological level*, and more than half of key muscle functions below the neurological level of injury (NLI) have a muscle grade less than 3 (Grades 0-2).

D = Motor incomplete. Motor function is preserved below the neurological level*, and at least half (half or more) of key muscle functions below the NLI have a muscle grade ≥ 3 .

E = Normal. If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive an AIS grade.

* For an individual to receive a grade of C or D, i.e. motor incomplete status, they must have either (1) voluntary anal sphincter contraction or (2) sacral sensory sparing and sparing of motor function more than three levels below the motor level for that side of the body. The International Standards at this time allow even non-key muscle function more than 3 levels below the motor level to be used in determining motor incomplete status AIS B versus C.

NOTE: When assessing the extent of motor sparing below the level for distinguishing between AIS B and C, the **motor level** on each side is used, whereas to differentiate between AIS C and D (based on proportion of key muscle functions with strength grade 3 or greater) the **neurological level of injury** is used.



Steps in Classification

The following order is recommended for determining the classification of individuals with SCI.

1. Determine sensory levels for right and left sides.
 The sensory level is the most caudal, intact dermatome for both pin prick and light touch sensation.

2. Determine motor levels for right and left sides.
 Defined by the lowest key muscle function that has a grade of at least 3 (on supine testing), providing the key muscle functions represented by segments above that level are judged to be intact (graded as a 5).
 Note: In regions where there is no myotome to test, the motor level is presumed to be the same as the sensory level. If testable motor function above that level is also normal.

3. Determine the neurological level of injury (NLI).
 The refers to the most caudal segment of the cord with intact sensation and antigravity (3 or more) muscle function strength, provided that there is normal (intact) sensory and motor function rostrally respectively.
 The NLI is the most cephalad of the sensory and motor levels determined in steps 1 and 2.

4. Determine whether the injury is Complete or Incomplete.
 (i.e. absence or presence of sacral sparing)
 If voluntary anal contraction = **No** AND all S4-S5 sensory scores = 0 AND deep anal pressure = **No**, then injury is **Complete**.
 Otherwise, injury is **Incomplete**.

5. Determine ASIA Impairment Scale (AIS) Grade:
 Is injury Motor Complete? If YES, AIS=A and can record ZPP (lowest dermatome or myotome on each side with some preservation)

Is injury Motor Complete? If YES, AIS=B
 (No-voluntary anal contraction OR motor function more than three levels below the motor level on a given side, if the patient has sensory incomplete classification)

Are at least half (half or more) of the key muscles below the neurological level of injury graded 3 or better?

NO AIS=C YES AIS=D

If sensation and motor function is normal in all segments, AIS=E
 Note: AIS E is used in follow-up testing when an individual with a documented SCI has recovered normal function. If at initial testing no deficits are found, the individual is neurologically intact; the ASIA Impairment Scale does not apply.

Figure 1.2 International Standards for Neurological Classification of SCI (ISNCSCI) Exam Worksheet (from: http://www.asia-spinalinjury.org/elearning/ISNCSCI_Exam_Sheet_r4.pdf; Publication permitted).

bilaterally with manual muscle testing. The results are summed to produce overall sensory and motor scores and are used in combination with evaluation of anal sensory and motor function as a basis for the determination of ASIA Impairment Scale (AIS) classification. The ISNCSCI differentiates AIS A, B, C, D and E. A complete SCI is defined as a lesion with no sensory or motor function preserved in the lowest sacral segments, S4 and S5. The ISNCSCI classification and description of severity (AIS) is given in Figure 1.2.

The level of the lesion divides the SCI population roughly into two groups a) persons with tetraplegia (lesions at or above the level of T1), with impairment of sensory and/or motor functions of the upper (see Table 1.1 for muscle innervation of the shoulder) and lower extremities, and trunk, and b) persons with paraplegia (lesions below T1), leaving the upper extremities intact, yet involving lower extremities and trunk. Control of the primary muscle for inspiration, i.e. the diaphragm, is located in the higher areas of the cervical spinal cord, i.e. at or above C4. Persons with a lesion in this area are likely in some way to be dependent on ventilator support.² The blood vessels, heart, respiratory tract, sweat glands, bowel, urinary bladder, and sexual functions are under nervous system control: autonomic (involuntary), somatic (voluntary), or both. With a SCI, there might be an imbalance in the autonomic nervous system (ANS) function, especially in lesion levels above T5.³ The International Standards to document remaining Autonomic Function after Spinal Cord Injury (ISAFSCI) is a guideline to describe autonomic function in persons with SCI. It is proposed to be used as an adjunct to the ISNCSCI including the AIS.³

EPIDEMIOLOGY OF SPINAL CORD LESION

Prevalence and incidence

Worldwide prevalence and incidence of SCI

In 2013 the World Health Organization (WHO) and International Spinal Cord Society launched the Report on International Perspectives on Spinal Cord Injury (IPSCI).^{5, 6} This report identifies and discusses the global prevalence and incidence data of SCI, and clearly reveals its limitations. Prevalence figures vary widely among nations, from 280 per million population in Finland⁷ and 1298 per million in Canada.⁸ In term of incidence large variation exists (ranging between 13 and 53 cases per million population) as well as inconsistent trends. Incidence of traumatic SCI has remained stable⁹ or increasing¹⁰ in some countries, whereas in other countries incidence has been decreasing.^{5, 7, 8} Thus, the IPSCI report concludes that given the paucity of the available data, it is not possible to derive meaningful

data for the global incidence of SCI and that there is a great need to systematically collect worldwide data and improve data quality.

In adults, the IPSCI report found a higher frequency of traumatic SCI (TSCI) in males, as well in young adults and the elderly. For young adults road traffic accidents were the main cause of TSCI, whereas in the elderly falls were the leading cause of TSCI.⁵ No grouped data on the prevalence of persons with tetraplegia, paraplegia, conus cauda syndrome or cauda equina syndrome are given in the IPSCI report.

For non-traumatic SCI (NTSCI), available data on prevalence and incidence are even more scarce. The IPSCI report discusses only two recent studies with sufficient data quality on the prevalence of NTSCI (adult and pediatric).⁵ Prevalence of NTSCI in Canada was 1226 per million population, whereas in Australia a prevalence of 367 per million population was found.^{8, 11} Regarding incidence the NTSCI incidence rate in Canada is estimated at 68 per million,⁸ while the Australian incidence rate is 27 per million¹¹⁻¹⁴ and in Spain this figure is as low as 11.4 per million.¹⁵

Epidemiology of SCI in the Netherlands

In 2010 the incidence of TSCI in the Netherlands was estimated to be around 11.7 per million population.¹⁶ The most frequent etiologies of TSCI were falls, traffic accidents and sports. The majority of the patients were male (74%), 69% of the persons suffered a tetraplegia and in 65% the SCI was defined as neurologically incomplete. Age distribution showed a clear peak in persons over 60 years of age (53%). Of those with TSCI only 49% of all patients admitted to an acute care hospital were referred to one of the eight rehabilitation centers with a specialized spinal cord unit. Especially persons with an incomplete SCI were more often not referred to a specialized SCI rehabilitation center.¹⁶

Unlike TSCI, the prevalence and incidence of NTSCI in the Netherlands is largely unknown. Of the patients with an NTSCI that were discharged from an in SCI-specialized rehabilitation center between 2006 and 2010, the mean age was 55 years and over 50% were male. Most persons had a paraplegia (77%) and incomplete lesion (69%). Most frequent etiologies were degeneration (26%), vascular disease (22%), benign tumor (16%), and malignant tumor (15%).¹⁷ The number of patients with NTSCI admitted to a rehabilitation center probably underestimates the national incidence of persons with NTSCI due to the fact that most of the persons with a NTSCI have a limited life expectancy and are less likely to be admitted to a SCI rehabilitation center.

Medical and rehabilitation care in the Netherlands

Approximately 300–400 persons are admitted to an in SCI-specialized rehabilitation center per year as a consequence of a new TSCI or NTSCI.¹⁸ Median length of acute hospital stay after TSCI is 25 days depending on the patients' physical state and the possibility for admission to a rehabilitation center.¹⁶ Length of stay (LOS) of inpatient rehabilitation in both TSCI and NTSCI varies considerably, with a median stay of 155 days. A Dutch single center study showed that for NTSCI median LOS in inpatient rehabilitation was 61.0 days (interquartile range [IQR], 38.3–111.8).¹⁷ For example, persons with a tetraplegia showed to have a longer LOS (median 301 days) compared to those with paraplegia and completeness of injury was associated with a longer LOS. Most patients were discharged home (84%) after first rehabilitation.¹⁸

All eight Dutch Rehabilitation centers specialized in SCI rehabilitation form the interdisciplinary Dutch Flemish Spinal Cord Society (DuFCoS at www.nvdg.org), which discusses and decides on, among others, guidelines, (new) therapies and research topics. The DuFCoS is a member body of the International Spinal Cord Society (ISCoS) (www.ISCOS.org.uk).

Epidemiology of SCI in Switzerland

Recently, a retrospective multicenter medical record study was performed as part of the Swiss Spinal Cord Injury Cohort Study (SwiSCI; see for more information www.swisci.ch).^{19,20}

Preliminary data of this retrospective study identified 820 persons with a newly acquired TSCI patients admitted for first rehabilitation between 2005 and 2011. The median age was 46 years and most of the patients were male (74%). The crude annual incidence rate was estimated at 18.2 per million population. Sports and leisure activities were the main causes of TSCI (37%), followed by transport-related accidents (33%). Falls were the main cause of TSCI (78%) in elderly persons over 76 years of age.²¹

The SwiSCI Cohort Study also identified 596 persons with a newly acquired NTSCI that were admitted for first rehabilitation in one of the four Swiss rehabilitation centers for SCI. The majority of those persons was male (59%) and the median age of the total group was 64 years. At admittance, 11% had an AIS score of AIS A, 9% AIS B, 14% AIS C and 31% AIS D; at discharge, roughly 55% had an AIS D. Vertebral column degenerative disorders accounted for the largest proportion of NTSCI (26%) followed by vascular disorders and neoplasms. Due to the probable underrepresentation of persons with a NTSCI, no national incidence rates of NTSCI were calculated.²²

Medical and rehabilitation care in Switzerland

In Switzerland four rehabilitation clinics offer specialized medical care and rehabilitation facilities for patients with SCI: the Swiss Paraplegic Centre (SPZ), REHAB Basel, Clinique Romande de Réadaptation (CRR) and the University Clinic Balgrist. The length of acute hospital stay after SCI in Switzerland is unknown, but is likely also to depend on the patients' physical state and the opportunities for admission to a rehabilitation center. The Swiss Paraplegic Centre, a 140-bed center, in addition to rehabilitation, offers acute care (including an Intensive Care Unit) and facilities for operative interventions (www.paranet.ch).

In the medical record study of the SwiSCI cohort study the median LOS of inpatient rehabilitation for TSCI was 178 days (range: 82 to 274 days) for patients with a tetraplegia and 94 days (range: 107 to 180 for patients with ASIA score D and A respectively) for persons with a paraplegia. Overall 77% of the patients were discharged home after first rehabilitation.²¹ For NTSCI median LOS was found to vary between 58 days for patients with SCI due to vertebral column disease and 119 days for patients with SCI due to infections. Again, most (66%) patients were discharged home after first rehabilitation.²²

Three of the Swiss SCI centers join the Swiss Society of Paraplegia (SSOP at www.ssop.ch) an organization that discusses and decides on, among others, guidelines, (new) therapies and research topics.

Mortality and life expectancy

The recently published IPSCI report found that persons with SCI are 2 to 5 times more likely to die prematurely than persons without SCI, and that mortality risk depends on level and severity of the injury.⁵ This conclusion was based on recent Finnish²³ and Australian studies²⁴, which showed that persons with a tetraplegia have a higher risk for mortality compared to persons with a paraplegia, and that there is a higher risk of mortality for persons with a complete lesion compared to those with an incomplete lesion.²⁴

In addition, the IPSCI report also found that life expectancy has increased during the last decades, especially in developed (high-income) countries.⁵ This might reflect the improvements in clinical rehabilitation medicine, technology and care for persons with SCI over the past decades in developed countries. However, caution is warranted, since a recent study by DeVivo et al., which describes the situation in the United States of America (USA), stated that recent gains in general population life expectancy are *not* reflected in the SCI population.²⁵

Currently, no reliable data on mortality and life expectancy after SCI in the Netherlands and Switzerland exist.

SECONDARY HEALTH CONDITIONS IN SCI

One of the main reasons for the increased mortality and limited life expectancy in persons with SCI is the vulnerability for secondary health conditions (SHCs).^{26, 27} The terminology of SHCs has been discussed in a paper by Jensen et al.²⁸ The authors pointed out that it is important to discriminate between common SHCs, which may develop independent of the primary health condition (e.g. Parkinson's disease), and SHCs that are specific to a primary health condition such as development of pressure sores in SCI. Furthermore, among the SHCs that are specific to SCI, Jensen et al. stated that it is important to distinguish two developmental pathways. Firstly, certain SHCs may directly relate to the neurological damage of the spinal cord, for example autonomic dysreflexia. Secondly, SHCs may indirectly result from ensuing factors or consequences of impairment following SCI. For example, shoulder pain may result from arthrosis in the shoulder joint due to overuse of the shoulder complex; or metabolic syndrome may arise as a consequence of the metabolic changes caused by SCI and the impairment-related physical inactivity of individuals with SCI. Finally, SCI may accelerate the onset of the normal aging process as indicated by the higher age-specific incidence of common multifactorial health conditions, particularly those involving the musculoskeletal, endocrine and cardiovascular systems.^{29, 30}

Typical SHC in persons with SCI include pressure ulcers,^{31, 32} urinary tract infection,^{33, 34} cardiovascular complications,^{35, 36} osteoporosis and lower-limb fractures,^{37, 38} neuropathic pain,^{33, 39} spasticity,⁴⁰ respiratory infections^{41, 42} and musculoskeletal pain.³³ In a recent community study musculoskeletal pain, including shoulder pain, was one of the most frequently reported SHCs (62.3–7.1%).³³

Health-related QOL may be reduced post-SCI, especially in individuals with medical complications.^{43, 44} Having a high impact on long-term outcomes, health-related behaviors are of crucial importance in maintaining health, especially in persons with SCI. The harmful effects of unhealthy behaviors such as physical inactivity or overweight are thought to be greater in persons with SCI than in able-bodied persons.⁴⁵ It has been shown that persons living with SCI are at increased risk of being physically inactive⁴⁶ and overweight.^{45, 47} An estimated 80% of the people with SCI is wheelchair dependent. Consequently, upper-body work is typical in daily life and 24/7. Apart from upper body overuse, this may lead to an

inactive lifestyle. Physical inactivity (mainly sitting hours) has shown to be one of the main risk factors for cardiovascular disease (CVD) in the able bodied population.⁴⁸ CVD is one of the main causes of death in persons with SCI.^{49, 50} Supposedly, shoulder impairment contributes to physical inactivity, which in turn can lead to deconditioning of the shoulder complex, leading again to an increased shoulder impairment. Therefore, preservation of shoulder health should be a main focus in the rehabilitation of persons with a SCI.

To understand the full burden of shoulder impairment in persons with SCI, comprehensive longitudinal cohort studies are needed to measure time and age-related change.⁵¹ The ICF provides a framework that makes it possible to better understand the consequences and impact of SHCs.⁵²

UNDERSTANDING THE CONSEQUENCES OF SCI: THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

The consequences of a SCI are tremendous. Besides the health condition itself and development of SHCs and its consequences on body structures (for example, fracture of the spine or ischemic infarction of the spinal cord) and body functions (for example loss of muscle power), a SCI affects the ability to perform activities and to participate. The typical spectrum of activity limitations and participation restrictions relate to mobility such as transfers and locomotion,⁵³⁻⁵⁸ self-care activities such as bathing, dressing, and toileting,^{59, 60} difficulties in regaining work, maintaining social relationships, participating in leisure activities and being active members of the community.^{61, 62}

The ICF provides a model of functioning and disability that creates conceptual clarity for data collection in research and clinical practice and health care in general.⁵² The ICF describes the effects of the health condition in relation to three levels of human functioning: body structures and functions, activities and participation. These levels are influenced by personal factors such as age, gender and self-esteem and by environmental factors such as availability of assistive devices, rehabilitation and health care facilities, social support, religion or financial and economic resources. All these aspects are assumed to potentially interact with each other (Figure 1.3). For several health conditions, teams of experts have developed so-called ICF Core Sets; these Core Sets provide a selection of the, for that health condition, most relevant ICF categories necessary to describe a person's functioning for the specific health condition. For SCI, brief and comprehensive ICF Core Sets for the early

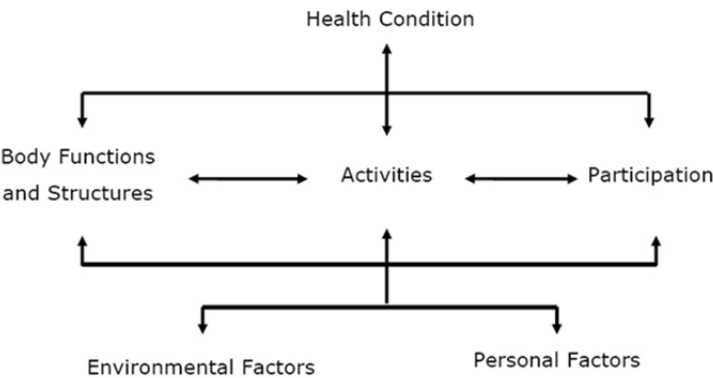


Figure 1.3 The International Classification of Functioning, Disability and Health (ICF) model on disability and health (WHO 2001).⁵²

post-acute and long-term context provide a selection of ICF categories most relevant for the description of functioning in persons with a SCI.^{63, 64}

This thesis uses the model of the ICF to describe the consequences of shoulder problems in persons with a SCI.

SHOULDER PROBLEMS IN PERSONS WITH SCI

Functional anatomy and vulnerability of the shoulder complex

The shoulder complex comprises of the humerus, thorax, scapula and clavicle and its four articulations: the sternoclavicular joint (SC joint); the acromioclavicular joint (AC joint); the glenohumeral joint (GH joint); and the scapulothoracic gliding plane (Figure 1.4). By nature of its functional anatomy, the mobility of the shoulder complex is wide in which a diversity of muscles play a crucial role in orientation and stabilization of the hand and arm in space. In the glenohumeral joint the humeral head is large compared to the glenoid. Stabilization of the glenohumeral joint is warranted mainly by the four rotator cuff muscles, while other muscles are mostly responsible for positioning and stabilization of the complex to the thorax and for positioning and movement of the arm (Table 1.1). This unique system allows the upper extremity a wide range of motions, covering almost 65% of a sphere. This wide range of mobility, together with elbow motion, allows positioning of the hand almost anywhere within the work space and therefore to use the arm and hand in many

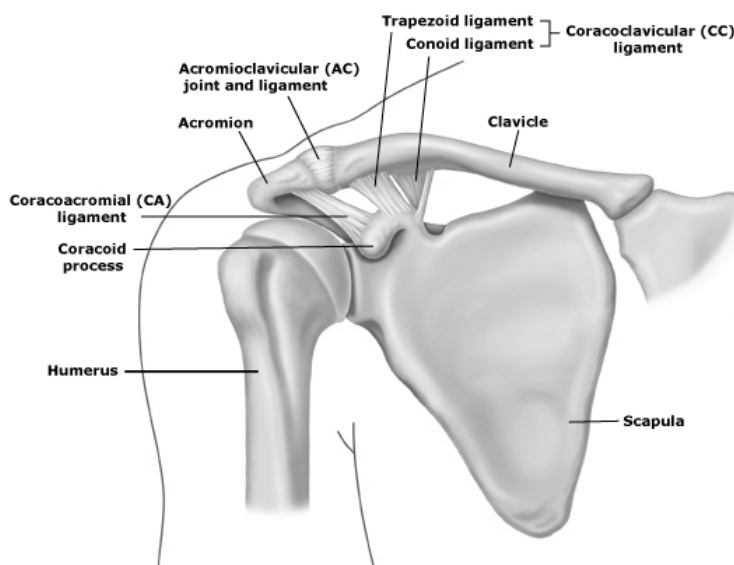


Figure 1.4 Anatomy of the shoulder complex (www.uptodate.com).

different daily activities (for example, reaching, intimate care, grooming). Full mobility is dependent on well-coordinated motion in all joints of the shoulder complex. However, the shoulder complex with the delicate balance between movement and stability is vulnerable for overuse.⁶⁵⁻⁶⁷

The nerves of the cervical spinal cord innervate the muscles of the shoulder complex. An overview of the most important muscles of the upper extremity, especially of the shoulder and their innervation is displayed in Table 1.1. Depending on the level and completeness of SCI several or all muscles of the shoulder may not be innervated. This neuromuscular deficit may cause a so-called ‘instability’ of the shoulder joint.

Understanding the development of shoulder impairments in SCI

For many persons, hand-rim wheelchair propulsion becomes a necessity after SCI and it will be the main mode of mobility in daily activities. The hand-rim wheelchair has many advantages, being small, maneuverable and transportable. Yet, hand-rim wheelchair propulsion has been shown to be physiologically and mechanically straining.^{53, 54, 69-76} Wheelchair dependency also implies that persons with a SCI need to perform several transfers each day (from bed to wheelchair, from wheelchair to shower or from wheelchair to

Table 1.1 Shoulder muscles and their main innervation (based on figure by Kirsch JRRD, 2001)⁶⁸

	Spinal segment							
	C2	C3	C4	C5	C6	C7	C8	T1
Scapular muscles	m.trapezius							
		m.levator scapulae						
			m.rhomboideus					
				m.serratus anterior				
Thoracohumeral muscles				m.pectoralis major				
					m.pectoralis minor			
					m.latissimus dorsi			
				m.teres major				
Glenohumeral muscles			m.supraspinatus					
			m.infraspinatus					
				m.subscapularis				
				m.teres minor				
				m.deltoideus				
				m.coracobrachialis				
Elbow flexors				m.biceps				
				m.brachialis				
				m.brachioradialis				
Elbow extensors					m.triceps			

car and vice versa), perform more overhead activities, while many persons perform weight-relief maneuvers to prevent pressure sores. Overhead activities are described as a risk factor for the development of shoulder impingement syndrome.⁷⁷ Weight-relief lifting^{73, 74, 76-78} and sitting pivot transfers are characterized by high forces, substantial angular displacements and velocities of the trunk and upper extremities.⁷⁹⁻⁸² Besides, during wheelchair propulsion, the scapula moves towards a position of increased downward rotation, anterior tilt and protraction with an increase in load, hence again increasing the risk of impingement.⁸³

A common understanding concerning the etiology of shoulder problems in persons with SCI is that repetitive and/or high biomechanical loads resulting from wheelchair use,^{69, 70, 73-76, 84-86} transfers^{73, 76, 78} and weight-reliefs,^{79-82, 87-89} in combination with an increased

susceptibility of the joint resulting from neuromuscular deficits and imbalance, lead to repetitive micro-trauma and consequently to an 'overuse' injury. This in turn might increase the risk of developing secondary musculoskeletal health problems of the shoulder such as early arthrosis in persons with a SCI. An attempt to describe a model for the development of shoulder problems in persons with SCI was made by Pentland and Twomey,⁹⁰ Requejo et al.⁹¹ and Figoni et al.⁹² Pentland and Twomey described a linear and unidirectional conceptual model suggesting the individual's physical predisposition (including, e.g., genetics, previous trauma, pre-existing disease) to be the starting point for the development of upper-limb problems in which behavior and lifestyle, age-related changes in the musculoskeletal system, and environmental factors interact with the person.⁹⁰ Requejo et al. used the ICF as a framework to describe a multidimensional model for shoulder pain, where shoulder pain, other body functions, body structures, activities, participation, environmental and personal factors interact with each other in multiple directions.⁹¹ Based on a literature review on associations of shoulder pathology/pain after SCI, Figoni et al. modified the model proposed by Requejo et al. by differentiating between modifiable and unmodifiable factors and between risk and protective factors.⁹² All of the proposed models underline the multifactorial etiology of shoulder problems in persons with SCI.

Structural changes of the shoulder after SCI (body structures)

Several authors have described changes in shoulder structures after SCI. Almost all studies included patients with chronic SCI and most studies had a cross-sectional design. Commonly described structural changes are degenerations,⁹³ impingement,⁹⁴ capsular contracture or capsulitis,⁹⁴ rotator cuff tears (RCT),⁹⁴⁻⁹⁷ anterior instability,⁹⁴ AC joint changes,⁹⁸⁻¹⁰² GH joint arthrosis,⁹⁸ osteoarthritis,⁹⁹ coracoacromial ligament thickening,^{99, 102} biceps tendon changes,¹⁰³ changes in the supraspinatus muscle¹⁰⁰ and changes in humeral thickness.¹⁰⁴

These changes in structure are considered a potential cause of shoulder pain in persons with SCI. An overview of the available literature on structural changes of the shoulder after SCI is given in Appendix 1.

Also other structural changes, not specific for persons with SCI may be present (but perhaps occur more often) in persons with SCI. Examples include avascular necrosis of the glenohumeral joint, subdeltoid bursitis, deltoid syndrome, scapulocostal syndrome¹⁰⁵ and less common causes such, suprascapular nerve entrapment and quadrilateral space syndrome and referred pain from the neck, spine and brachial plexus.¹⁰⁶

Shoulder pain and shoulder range of motion after SCI (body functions)

Shoulder pain is common among persons with SCI. Several publications describe the prevalence of shoulder pain after SCI. Mean shoulder pain prevalence during the acute phase after SCI was found to be around 48% (range 3–100) and in the chronic phase after SCI 50% (range 3–85).^{59, 90, 94, 98, 101, 102, 107-146} The prevalence of shoulder pain in SCI is approximately three times higher compared to prevalence of shoulder pain in the general population.¹⁴⁷ Epidemiological studies have suggested that shoulder pain in persons with SCI is associated with age,^{108, 119, 122, 125, 132, 139, 142, 143} time since injury (TSI),^{119, 122, 125, 139} lesion characteristics such as level of injury and completeness of SCI,^{114, 119, 126-128, 132, 133, 138, 141, 145} shoulder ROM,^{98, 143} duration of bed rest,¹³² applied interventions,¹⁴³ activities,^{111, 119, 121, 122, 131, 134, 141} higher shoulder joint forces and moments¹⁰² and use of assistive technology (AT; such as electric wheelchairs).^{124, 126}

Studies on prevalence and course over time of shoulder ROM in persons with SCI are limited. The studies available mostly include small samples and/or often have a cross-sectional study design. Shoulder ROM prevalence is estimated to be around 40% (range 9–70%) in the acute phase and 30% (range 9–70%) in the chronic phase after SCI.^{98, 115, 116, 132, 148} Determinants for limited shoulder ROM in literature include male gender, longer TSI, AC joint narrowing, lower Functional Independence Measure (FIM) score, poorer health, spasticity medication use and presence of shoulder pain.^{98, 116, 132} Appendix 2 gives an overview of currently available literature concerning prevalence on shoulder pain and ROM limitations and its determinants.

Current knowledge on activities and participation in relation to shoulder pain and shoulder ROM limitations after SCI

Although it has been suggested that shoulder pain might negatively affect activities and participation, as well as QOL, the association of shoulder ROM limitations and shoulder pain with activities and participation is only scarcely described and show conflicting results.^{98, 116, 122, 125, 126, 128, 131-135, 137, 140, 142, 148} An overview of current literature on shoulder pain and shoulder ROM, and their association with activities and participation is given in Appendix 2.

As can be seen in the overview of literature in Appendices 1 and 2, most studies are cross sectional, include mostly small sample sizes and selected (convenience) patient groups. A paucity of literature exists on the longitudinal perspective, describing shoulder problems in persons with SCI over time, LOS, TSI or ageing. Therefore the (mechanism of the) development of shoulder problems and course over time in persons with SCI remains

unclear. To improve goal setting and to optimize intervention programs in in- and outpatient rehabilitation and follow-up care, better understanding of the course of shoulder problems in the first years after onset of SCI, its determinants and the association of shoulder problems with activities and participation is needed.

RESEARCH CONTEXT OF THE THESIS

The Umbrella project: restoration of mobility in spinal cord injury rehabilitation

The Umbrella project 'Restoration of mobility in spinal cord injury rehabilitation' is a prospective cohort study, which is part of the Dutch research program 'Physical strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of persons with spinal cord injury'.¹⁴⁹ The main purpose of this project is to investigate the course of restoration of mobility on the levels of body functions, activities and participation during and after SCI rehabilitation, and to describe possible determinants thereof (www.scionn.nl).

An extensive measurement protocol was administered, including assessment of lesion characteristics, health conditions, body functions, basic skills (activities), social functioning (participation), QOL, use of aids (environmental factors) demographics and psychosocial factors (personal factors) and psychological factors. Presence and severity of shoulder pain and shoulder range of motion were assessed within the study.

Measurement times in this study were: when a person was able to sit in a wheelchair for 3–4 hours at a time (Start); three months later (3M); at discharge from inpatient rehabilitation (Discharge); one year after discharge (1Y).

Included were persons with a newly acquired SCI in one of the eight rehabilitation centers with specialized SCI units in The Netherlands between August 2000 and July 2003. Participants were eligible to be included in the study if they had a newly acquired SCI, were between 18 and 65 years of age, were classified as AIS A, B, C or D, and were expected to remain, at least partly, hand-rim wheelchair dependent. Excluded were those persons with a progressive disease, psychiatric problems or who had insufficient understanding of the Dutch language and were therefore unable to understand the purpose of the study.

SPIQUE

The SPIQUE project consists of a follow-up measurement 5 years (5Y) after discharge of the persons with SCI who participated in the Umbrella project. Measures that were assessed in the Umbrella project were, to a large extent, included in the SPIQUE project. A total of 145 persons with SCI participated in the SPIQUE study.

The outcomes of the Umbrella project, the SPIQUE project, were published in over 50 peer-reviewed papers and ten PhD Theses (www.scionn.nl).

Swiss Paraplegic Research

It is the mission of Swiss Paraplegic Research to sustainably improve the situation of people with paraplegia or tetraplegia through clinical and interdisciplinary research in the long-term. The areas that are aimed to be improved are functioning, social integration, equality of opportunity, health, self-determination and QOL. It is the proclaimed goal of Swiss Paraplegic Research to promote the study of health from a holistic point of view, by focusing on the 'lived experience' of persons with health conditions and their particular interaction with society¹⁵⁰ (www.paraplegie.ch).

Swiss Paraplegic Centre

The Swiss Paraplegic Centre is located in Nottwil, Switzerland and is Europe's leading 140-bed center for acute care and rehabilitation of persons with spinal cord injuries and diseases. It has the objective of delivering holistic, lifelong care for patients. Within the Swiss Paraplegic Centre a specialized interdisciplinary shoulder team for persons with SCI including physicians, radiologists, physiotherapist, occupational therapists, nurses and researchers assure 'best in class' clinical and research expertise (www.paraplegie.ch).

A successful research collaboration in a broad range of topics (e.g. pulmonary health, shoulder biomechanics and hand-cycling, upper extremity health, psychological health) between the University Medical Center Groningen (UMCG), Swiss Paraplegic Research, as well as the Dutch Umbrella and SPIQUE studies resulted in several scientific publications and the finalization of, so far, two joined PhD theses.^{151, 152}

AIM AND OUTLINE OF THE PRESENT THESIS

As stated by the Healthy Ageing Campus Netherlands: *“The challenge is Healthy Ageing: growing older in a healthy and active way. Maintaining good health well beyond pension age would greatly enhance quality of life and well-being, as well as labour participation, informal care capacity and other significant contribution to society. However, new knowledge is required about the influence of these factors, and how they interact with one another.”* (Quote at <http://www.healthyageingcampus.nl/about/healthy-ageing>).

For persons with a SCI, a prerequisite for healthy ageing is an optimal shoulder health in order to enhance optimal performance in activities and participation.

Therefore the aim of the present thesis is to gain: 1) understanding in structural changes, prevalence and course of shoulder problems (pain and ROM) over time and, 2) to study the complex association between aspects of shoulder structure, shoulder function and activities and participation using the ICF as a framework. As such, this thesis intends to offer a step towards healthy ageing of persons with a SCI.

This thesis studied five research questions:

1. Is there a relation between shoulder pain and structural changes of the shoulder/AC joint in persons with a SCI? (Study 1)
2. Which shoulder pain trajectories in persons with SCI can be described and which predictors for belonging to a specific trajectory can be found? (Study 2)
3. What is the prevalence of shoulder ROM limitations, its course over time and determinants during and 1 year after clinical rehabilitation in persons with a SCI? (Study 3)
4. What is the association between a limitation in shoulder ROM and activities and participation 1 year after discharge in persons with a SCI? (Study 4)
5. What is the association of shoulder pain and shoulder ROM limitations at discharge from inpatient rehabilitation and activities and participation 5 years after clinical rehabilitation in persons with a SCI? (Study 5)

Figure 1.5 shows the variables and used outcome measures in this thesis within the biopsychosocial model of the ICF.

In Table 1.2 the ICF categories/specifications and their consecutive measurement instruments at specific test occasions used in this thesis are presented.

Table 1.2 ICF categories/specification and consecutive measurement instruments used in this thesis

ICF category	Specification	Measurement instrument	AC joint	Umbrella study		Measurement times					SPIQUE study
				Start	3M	Discharge	1Y	5Y			
HC	Spinal cord Injury (neurological classification)	ISNCSCI	X	X	X	X	X				X
PF	Gender	-	X	X							
PF	Age	-	X	X							
PF	TSI	-	X	X	X	X	X				X
PF	BMI	Mass/height		X							
s720	Structures of shoulder region	Classification of Shubin-Stein (AC joint arthrosis)	X								
b280	Pain (shoulder)	NRS	X	X	X	X	X				X
b710	Mobility of (shoulder) joint	ROM/Goniometry		X	X	X	X				
b735	Muscle tone functions (Spasticity of elbow muscles)	Clinical assessment of spasticity		X							
b410-b449	Functions of cardiovascular and respiratory system	Peak Wheelchair Exercise test (POpeak)									X
d4-d5	Mobility and self-care	Functional independence in activities (FIM)		X		X	X				X
d465	Mobility using aids	WST				X					X
d6-d8	Domestic life/ interpersonal interactions and relationships/major life areas	PASIPD				X	X	X			X
d6-d8	Domestic life/ interpersonal interactions and relationships/major life areas	SIPSOC									X
d850	Remunerative employment	Hours of work per week									X

Abbreviations: AC joint = acromioclavicular joint, BMI = Body mass index, FIM = Functional Impairment Measurement, ISNCSCI = International Standards for Neurological Classification of Spinal Cord Injury, NRS = Numeric Rating Scale, PASIPD = Physical Activity Scales for Individuals with Physical Disabilities, POpeak = peak aerobic power Output, ROM = Range of motion, IPSOC = Social Behaviour of the 68 Item Sickness Impact Profile, TSI = Time since Injury, WST = Wheelchair Skills Test.

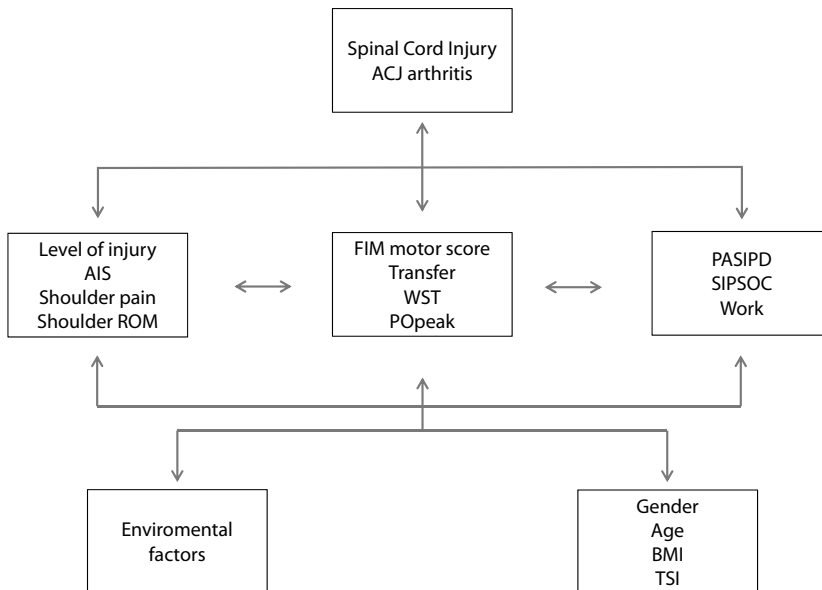


Figure 1.5 Variables and outcome measures within this thesis using the bio-psychosocial model of the ICF. Abbreviations: FIM = Functional Impairment Measurement, PASIPD = Physical Activity Scales for Individuals with Physical Disabilities, ROM = Range of motion, SIPSOC = Social Behavior of the 68 Item Sickness Impact Profile, TSI = Time since injury, UAL = Utrecht Activity List.

The results of the studies on the above-described research questions will be presented in chapters 2 to 6. Chapter 7 gives an overview of the main study results of this thesis, followed by a general discussion, including limitations of the thesis and suggestions for future research and clinical implications.

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Chapter 2

Acromioclavicular joint arthrosis in persons with spinal cord injury and able-bodied persons

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ABSTRACT

Objective: To compare prevalence, severity and risk of acromioclavicular (AC) joint arthrosis in persons presenting with shoulder pain between a spinal cord injury (SCI) and able-bodied population. In the SCI population, prevalence and severity of AC joint arthrosis were examined with respect to age, gender and lesion characteristics.

Methods: Retrospective analysis of medical records and magnetic resonance images (MRI) collected in an outpatient orthopaedics clinic.

Results: 68 persons with SCI and 105 able-bodied persons were included in the study. The overall MRI prevalence of AC joint arthrosis was 98% and 92%, respectively. In both groups AC joint arthrosis was frequently accompanied by MRI diagnosis of rotator cuff tears and biceps tendon ruptures. Sensitivity of clinical testing was found to be low in SCI (0.31) and in able-bodied persons (0.23). The odds of increasingly severe arthrosis were nearly 4 times higher in persons with SCI as compared to able-bodied persons ($p<0.0001$); about 72% lower in females as compared to males ($p=0.0001$); and 10% higher per additional year of age ($p<0.0001$). Arthrosis severity in the SCI group was weakly associated with time since injury, not with neurological classification of SCI or level of injury (paraplegia vs. tetraplegia).

Conclusion: SCI patients presenting with shoulder pain showed similar prevalence, yet more advanced AC joint arthrosis than able-bodied patients. Since early diagnosis of arthrosis is a prerequisite for the initiation of successful conservative interventions of shoulder deterioration, we recommend routine assessment of shoulder status including diagnostic imaging during check-ups.

INTRODUCTION

Shoulder pain is a frequently reported problem in persons with a spinal cord injury (SCI), with prevalences varying between 30 and 70%.¹⁻³ Overuse is described as a major cause of shoulder pain in wheelchair-dependent persons with SCI.⁴ Especially transferring and weight-relief lifting as well as wheelchair propulsion are related to a high and/or repetitive strain on the shoulder.⁵⁻⁷ Commonly encountered pathologies causing shoulder pain include subacromial impingement,⁸ tendinopathy and rotator cuff tears (RCT).⁹

In the able-bodied population arthrosis of the acromioclavicular (AC) joint has been described as a common source of shoulder pain that is often not recognized by clinicians and researchers¹⁰ and might masquerade other shoulder conditions. In SCI degenerative changes of the AC joint are less commonly described as a cause for shoulder pain.^{9,11} Among 28 persons with paraplegia, Boninger et al.¹¹ found a prevalence of 64% and 43% for AC joint degenerative joint disease and AC joint oedema, respectively. In the study of Akbar et al.⁹ the prevalence of AC joint arthrosis in persons presenting with and without pain was 43%, which was significantly higher than in the for age and gender matched control group (26%).

Early diagnosis and insight in the risk profiles of AC joint arthrosis in persons with SCI are relevant, because treatment options are reduced and often restricted to challenging surgical interventions with increasing arthrosis severity.

The aim of the present study was to investigate the prevalence, severity and risk of AC joint arthrosis by Magnetic Resonance Imaging (MRI), in persons with SCI, compared to an able-bodied population, both presenting with shoulder pain. A second aim was to study the sensitivity and specificity of clinical examination in persons using MRI as a gold standard. The third aim of the study was to investigate the association between level and neurological classification of SCI, age, gender and time since injury (TSI) with prevalence and severity of AC joint arthrosis in the SCI population. It was hypothesized that there would be an increase in the prevalence and severity of AC joint arthrosis in the elderly and those with a longer TSI and no relationship with gender, level and neurological classification.

METHODS

Study design

The present study was a retrospective analysis of medical records and MRI.

The study was approved by the ethical committee of the canton Luzern, Switzerland and is in accordance with the ethical standards in the 1964 Declaration of Helsinki.

Included were all persons with SCI as well as able-bodied persons, who presented with shoulder pain and were assessed at the outpatient orthopaedics clinic of the Swiss Paraplegic Center (Nottwil, Switzerland) between January 2007 and December 2009.

Participants

Participants were 18 years or older and SCI participants had to be wheelchair dependent. Excluded were participants with any systemic joint disease. From the patient records, date of birth and gender were retrieved. For participants with SCI, the TSI, the level of SCI (paraplegia vs. tetraplegia) and the neurological classification of SCI according to the International Standards for Neurological and Functional Classification of Spinal Cord Injury (ASIA Impairment Scale (AIS))¹² were also retrieved from patient records.

Assessments

Clinical assessment of the shoulder was performed in all patients using multiple tests. For AC joint arthrosis especially palpation of the AC joint and the cross body adduction test were included. For RCT several tests were performed, including cross-body adduction test, Lift-off test and Empty-can test. The clinical exam for AC joint arthrosis, respectively RCT, was scored positive if one of the tests was positive.

All participants underwent MRI following a standardized protocol as part of their medical check-up. All imaging was performed on a 3T MRT unit (Philips, Amsterdam, The Netherlands) with a shoulder coil and acquired with proton density weighted (PDW), PDW inversion recovery (SPAIR), T1 weighted and T1 weighted inversion recovery (SPIR) sequences after intra-articular contrast application. MRIs were assessed by an experienced musculoskeletal radiologist. Ten percent of the MRIs were re-assessed blinded to calculate the intra-rater reliability.

AC joint arthrosis severity and presence of bone oedema was classified according to the classification of Shubin Stein¹³ (Figure 2.1).

Tendons of the rotator cuff (m. supraspinatus, infraspinatus and subscapularis) as well as the long tendon of the biceps muscle were (assessed and) graded depending on tendinopathy, partial, transmural or complete rupture.

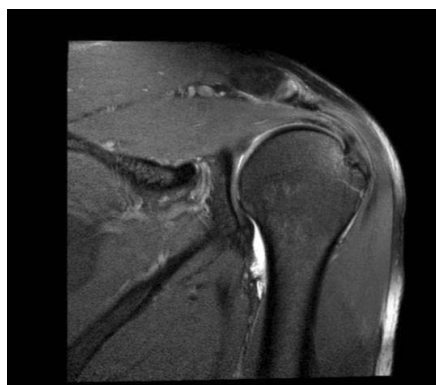
**A: Grade I****B: Grade II****C: Grade III****D: Grade IV**

Figure 2.1A–D Acromioclavicular joint arthrosis classified by Shubin-Stein: (A) Grade I; no capsular distension, no joint space narrowing, and no evidence of osteophyte formation, (B) Grade II; capsular distension, frequently an isolated finding but occasionally accompanied by mild joint space narrowing, (C) Grade III; capsular distension with a combination of joint space narrowing, subacromial fat effacement, and marginal osteophyte formation and (D) Grade IV; all of in Grade I, II and III mentioned findings in addition to marked joint space irregularity and narrowing with large osteophytes. All images acquired with proton density weighted (PDW), PDW inversion recovery (SPAIR), T1 weighted and T1 weighted inversion recovery (SPIR) sequences after intra-articular contrast application.

Analyses

Basic statistics were used to describe demographic characteristics, clinical tests, MRI and their associations. Ordered logistic regression (OLR) was used to evaluate adjusted odds ratios for more severe arthrosis in MRI findings (stepwise progressive from Grade 1 to Grade 4)

in univariable and a multivariable models, using study group (SCI vs. able-bodied), age (in years) and sex as predictor variables. In sensitivity analysis the effect of age was investigated as categorical variable (3 age groups: under 40; 40 to 59; and 60 or older). Effect modification was investigated by adding mutual interaction terms between the predictor variables to the multivariable model. The likelihood ratio test was used to estimate significance of effects. To verify the basic assumption parallel lines (i.e., same slopes) in OLR modelling the Brant test was used, as global test and for each variable separate.¹⁴ Risk factors for AC joint arthrosis severity in the SCI group were investigated in a separate model using TSI, age (in years), sex and AIS score (tested with 4 levels and tested A (complete) vs. B, C and D (incomplete) as predictor variables. Multiple imputation was used to account for the missing of the AIS score in one participant. In a second model the effect of level of injury as a risk factor for AC joint arthrosis severity was investigated, using TSI, age (in years), sex and level of injury (paraplegia vs. tetraplegia) as predictor variables. Alpha error was set at 0.05 and all reported p-values are two sided. Stata 11.2 software (StataCorp LP, Texas, USA) was used in statistical analysis. Chronbach's alpha was calculated to measure the intra-rater reliability of the MRI assessments.

RESULTS

Patient demographics

68 persons with SCI and 105 able-bodied persons were included in the study. Table 2.1 gives an overview of the participants' characteristics. The SCI and able-bodied group showed a similar distribution in age and sex. Within the SCI group, level of injury was paraplegia and tetraplegia in 72% and 28%, respectively. The predominant AIS score (80%) was A. The mean TSI was 23.3 years and not related to lesion level ($p=0.27$).

Table 2.2 displays the descriptives of clinical findings and MRI exam for AC joint pathology, RCT and biceps tendon tears and the p-values for between group differences.

Prevalence, severity of AC joint arthrosis, sensitivity and specificity of clinical examinations

The sensitivity and specificity of clinical examinations for AC joint arthrosis using MRI diagnosis as a gold standard is displayed in Table 2.3. Clinical examination in the SCI and able-bodied group showed high specificity (100% respectively 71%), but low sensitivity

(31% respectively 23%). Using 2-tailed Fischer's exact test showed no significant association between clinical exam and MRI findings ($p=1$ for SCI group and $p=0.66$ for able-bodied group). The low number of 'cases' per cell does not allow to calculate the differences of the association MRI-clinical assessment between the SCI and able-bodied group.

Table 2.1 Descriptive statistics of the study population

	SCI group	Able-bodied group	P-value
Number of persons	68	105	
Age (years, range)	51 (21–79)	53 (18–80)	0.40
Male (%)	53 (78%)	69 (66%)	0.085
Level of injury		n.a.	n.a.
Paraplegia (%)	49 (72%)		
Tetraplegia (%)	19 (28%)		
AIS score		n.a	n.a.
A	54 (80%)		
B	6 (9%)		
C	5 (7%)		
D	2 (3%)		
Unknown (missing)	1 (1%)		
Time since injury (years, range)	23 (0–48)	n.a.	n.a.

SCI = spinal cord injury; n.a. = not applicable; AIS = ASIA impairment scale.

Table 2.2 Descriptive statistics of clinical tests and MRI diagnosis of the population

	SCI group (n=68)			Able-bodied group (n=105)			P-value
	Positive	Negative	Unknown/ not judgeable	Positive	Negative	Unknown/ not judgeable	
Clinical exam							
AC joint	19 (28%)	43 (63%)	6 (9%)	21 (21%)	64 (60%)	20 (19%)	0.133
RCT	27 (40%)	39 (57%)	2 (3%)	40 (38%)	52 (50%)	13 (12%)	0.093
MRI diagnosis							
AC joint arthrosis	67 (99%)	1 (1%)	-	96 (91%)	9 (9%)	-	0.051
RCT overall	50 (74%)	13 (19%)	5 (7%)	74 (70%)	30 (29%)	1 (1%)	0.041
SSP	42 (62%)	21 (31%)	5 (7%)	64 (61%)	40 (38%)	1 (1%)	
ISP	25 (37%)	38 (56%)	5 (7%)	45 (43%)	59 (56%)	1 (1%)	
SSC	42 (62%)	21 (31%)	5 (7%)	54 (51%)	50 (48%)	1 (1%)	
Biceps tendon	38 (56%)	25 (37%)	5 (7%)	42 (40%)	62 (59%)	1 (1%)	0.004

SCI = spinal cord injury; AC joint = acromioclavicular joint; RCT = rotator cuff tear; SSP = supraspinatus muscle/tendon; ISP = infraspinatus muscle/tendon; SSC = subscapularis muscle/tendon; MRI = magnetic resonance imaging.

Table 2.3 Contingency table of clinical tests for AC joint arthrosis and findings on MRI in persons with SCI and able-bodied persons

		Clinical exam		
		Positive	Negative	Unknown
MRI findings in persons with SCI (n=68)	Positive	19 (28%)	43 (62%)	6 (9%)
	Negative	0 (0%)	1 (1%)	0 (0%)
MRI findings in able-bodied group (n=105)	Positive	19 (18%)	59 (56%)	18 (17%)
	Negative	2 (2%)	5 (5%)	2(2%)

Abbreviations: SCI = spinal cord injury; MRI = magnetic resonance imaging.

MRI findings in participants with SCI showed an overall prevalence of AC joint arthrosis of 98%. In the able-bodied group, prevalence of AC joint arthrosis on MRI was 92% (Figure 2.2). Bone oedema was present in 13% (n=9) in the SCI group and in 22% (n=23) in the able-bodied group.

Chronbach’s alpha intra-rater reliability was 0.95 for prevalence and severity of AC joint arthrosis and 0.77 for presence of bone oedema.

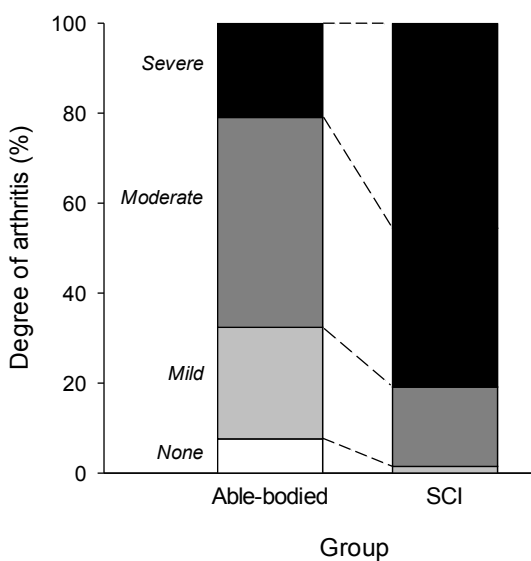


Figure 2.2 Degree of acromioclavicular joint arthrosis by group, as classified by Shubin-Stein.¹³ SCI = spinal cord injury.

Table 2.4 Unadjusted and adjusted odds ratios for AC joint arthrosis as derived from ordered logistic regression. P-values were obtained from likelihood ratio tests.

Variables	Unadjusted		Adjusted	
	Odds ratio (95% CI)	P-value	Odds ratio (95% CI)	P-value
Group				
Able-bodied	1		1	
SCI	2.70 (1.50–4.85)	0.0007	3.82 (2.03–7.21)	<0.0001
Sex				
Male	1		1	
Female	0.39 (0.22–0.72)	<0.0001	0.28 (0.14–0.54)	0.0001
Age (years)	1.07 (1.05–1.10)	0.002	1.10 (1.07–1.12)	

SCI = spinal cord injury.

Risk factors for AC joint arthrosis

The odds of increasingly severe arthrosis, holding all other variables constant, were nearly 4 times higher in persons with SCI as compared to able-bodied persons (adjusted odds ratio = 3.82, 95% CI: 2.03–7.21; $p < 0.0001$); about 72% lower in females as compared to males (adjusted odds ratio = 0.28, 95% CI: 0.14–0.54; $p = 0.0001$); and 10% higher per additional year of age (adjusted odds ratio = 1.10, 95% CI 1.07–1.12, $p < 0.0001$; Table 2.4). There was no indication of effect modification (tests of interaction: for Age*Study Group, $\chi^2 = 0.06$, $df = 1$, $p = 0.80$; for Sex*Study Group, $\chi^2 = 0.74$, $df = 1$, $p = 0.39$). The univariate analysis gave similar results, indicating that main effects are largely independent. Further, allowing for a non-linear effect of age did not improve model fit (for comparison of model with categorical age variable: $\chi^2 = 3.40$, $df = 2$, $p = 0.18$). Furthermore, there was no evidence for violation of the underlying parallel regression assumption (Brant test for combined variables: $\chi^2 = 4.83$, $df = 6$, $p = 0.56$; for separate variables: all $p > 0.35$).

Risk factors in persons with SCI

Arthrosis severity in the SCI group showed, controlling for the effects of sex and age, only a weak association with TSI (in years: adjusted odds ratio = 1.04, 95% CI 0.99–1.09, $p = 0.078$) and no association with AIS score (tested with 4 levels A, B, C, D: $p = 0.72$; tested A (complete) vs. B, C, and D (incomplete): $p = 0.29$) or lesion level (paraplegia vs. tetraplegia: $p = 0.32$).

DISCUSSION

The current study was performed to get more insight in the prevalence, severity and risk of AC joint arthrosis in person with SCI who presented with shoulder pain compared to an able-bodied population with shoulder pain and to study the association between level and neurological score of SCI, age, gender and (TSI) with prevalence and severity of AC joint arthrosis in the SCI population.

Prevalence, severity and risk of AC joint arthrosis in person with SCI who presented with shoulder pain compared to an able-bodied population with shoulder pain

The present comparative study showed a high prevalence of AC joint arthrosis on MRI in both persons with SCI (98%) and the able-bodied persons (92%). However, controlling for variation in age and sex, the odds of having an increasingly severe arthrosis for persons with SCI was found to be nearly 4 times higher.

The relation between clinical exam and MRI findings of AC joint arthrosis showed that clinical testing has a low sensitivity (or high type II error rate) in both groups, showing an underrepresentation of AC joint arthrosis by clinical testing. The Study by Brose et al., which investigated the presence of ultrasound abnormalities and physical examination findings in a male manual wheelchair users with SCI showed in 18% of the clinical exams AC joint tenderness. Ultrasound findings showed a positive trend with the Wheelchair User's Shoulder Pain Index (WUSPI) but statistical association between clinical exam and AC joint pathology on ultrasound findings was not described.¹⁵

The current study showed a higher prevalence of AC joint arthrosis on MRI in both persons with SCI and able-bodied persons than found in former studies assessing this topic using MRI. This difference in prevalence is likely related to specific study characteristics. A study of Cardogan et al.¹⁶ showed only a prevalence of 17% of AC joint degeneration in able-bodied persons presenting with pain in a primary care setting. Boninger et al.¹¹ found an overall prevalence of 30% in a population that included only persons with paraplegia with and without shoulder pain, who were of younger age and had a shorter time since injury (i.e., 11.5 years). Akbar et al. found a prevalence of AC joint arthrosis of 42% in persons with SCI and 26% in able-bodied persons.⁹ The study of Akbar et al. also included only persons with paraplegia. They found an odds ratio of having AC joint arthrosis for persons with SCI of 2.1 compared to those in the control group.

Similar to our study, Akbar et al. found a higher prevalence of shoulder pathology in person with SCI when controlling for age.⁹ In our study group, the odds of increasingly severe arthrosis, holding all other variables constant, were 10% higher per additional year of age. This result is also in line with the study of Pennington et al.,¹⁷ who studied radiological features of osteoarthritis of the AC joint and its association with clinical symptoms. The relation with age confirms the idea that AC joint arthrosis is related to repetitive strain.

Our study showed that the odds of increasingly severe arthrosis were about 72% lower in females as compared to males. This result differs from the finding of Pennington et al.,¹⁷ who did not find any association between gender and radiological features of osteoarthritis of the AC joint. Also the study of Schweitzer et al.,¹⁸ studying the AC joint fluid and determination of clinical significance with MRI found no relation with gender.

Association between level and completeness of SCI, age, gender and time since injury (TSI) with prevalence and severity of AC joint arthrosis in the SCI population

The analysis of arthrosis severity in the SCI group revealed, when controlling for the effects of sex and age, a weak association with time since injury and no association with AIS score or lesion level. This finding is surprising, since arthrosis of the AC joint is typically thought of as a result of repetitive strain injury and therefore age and time since injury was expected to be associated much stronger with AC joint arthrosis. In the one other study found addressing the relations between patient characteristics and prevalence and severity of AC joint arthrosis, the number of patients included in the study was too small to study any risk factors within the SCI group.¹⁹

Study limitations

The current study was performed retrospectively and therefore relevant determinants like physical activity (overhead sports), number of transfers and shoulder injury before SCI, were not assessed. For future studies, adding these variables would be of interest. Furthermore, shoulder pain was not assessed with a validated measurement instrument in this study. Standardized clinical tests to assess AC joint pathology, with for example the Paxinos²⁰ test would further increase the study quality.

CONCLUSION

The results of our study show a high prevalence of AC joint arthrosis in persons with SCI and able-bodied persons, however a more severe degree and more advanced stage of AC joint arthrosis was found in persons with SCI (controlled for sex, age and TSI). Sensitivity of clinical testing is found to be low. Routine assessment during check-ups, which includes assessment of shoulder pain, physical examination and diagnostic imaging (X-ray and when necessary MRI), might help to diagnose AC joint arthrosis at an earlier stage. Early diagnosis is a prerequisite for successful conservative interventions (e.g. optimizing transfer techniques, technique of wheelchair propulsion) of further shoulder deterioration.

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Chapter 3

Trajectories of **musculoskeletal shoulder pain** after spinal cord injury: Identification and predictors

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ABSTRACT

Objective/background: Although shoulder pain is a problem in up to 86% of persons with a spinal cord injury (SCI), so far, no studies have empirically identified longitudinal patterns (trajectories) of musculoskeletal shoulder pain after SCI. The objective of this study was: 1) to identify distinct trajectories of musculoskeletal shoulder pain in persons with SCI, and 2) to determine possible predictors of these trajectories.

Design/methods: Multicenter, prospective cohort study in 225 newly injured persons.

Outcome measure: Shoulder pain was assessed on five occasions up to 5 years after discharge. Latent Class Growth Mixture Modeling was used to identify the distinct shoulder pain trajectories.

Results: Three distinct shoulder pain trajectories were identified: (1) a 'No or Low pain' trajectory (64%), (2) a 'High pain' (30%) trajectory and (3) a trajectory with a 'Decrease of pain' (6%). Compared to the 'No or Low pain' pain trajectory, the 'High pain' trajectory consisted of more persons with tetraplegia, shoulder pain before injury, limited shoulder range of motion (ROM), lower manual muscle test scores or more spasticity at t1. Multiple logistic regression analysis showed two significant predictors for the 'High pain' trajectory (as compared to the 'No or Low pain' trajectory): Having a tetraplegia (OR=3.2; p=0.002) and having limited shoulder ROM (OR=2.8; p=0.007).

Conclusion: Shoulder pain in people with SCI follows distinct trajectories. At risk for belonging to the 'High pain' trajectory are persons with tetraplegia and those with a limited shoulder ROM at start of active rehabilitation.

INTRODUCTION

Although shoulder pain is a problem in up to 67% of persons with a spinal cord injury (SCI), so far, no studies have empirically identified longitudinal patterns (trajectories) of musculoskeletal shoulder pain after SCI.¹⁻⁵ Many people with spinal cord injury (SCI) depend on their arms for mobility and several activities of daily living (ADL), such as transferring from the wheelchair to the car. Therefore, they are at higher risk for problems associated with over-use of the shoulder compared to those without SCI.^{6,7} Of those persons with SCI and shoulder pain 86% also report limitations in daily activities¹⁻⁵ and in participation. For example, in 84% of persons with SCI, shoulder pain leads to a limitation in sport and leisure activities.^{2,8} Furthermore, shoulder pain is associated with lower perceived health⁹, lower quality of life,^{10,11} and increased use of assistive devices.¹²

Previous research has found predictors of musculoskeletal shoulder pain to be: older age, longer time since injury (TSI), higher Body Mass Index (BMI), lesion level (tetraplegia), muscle strength (inversely related), shoulder range of motion (ROM) and functional outcome (inversely related).^{11, 13-16} However, most of these findings are based on cross-sectional studies of persons with chronic SCI.¹⁷ Only a few studies on shoulder problems in SCI had a prospective longitudinal design.^{5, 11, 18} These studies model the group mean scores of shoulder pain over time which, although useful, may hide distinct patterns of change in shoulder pain after SCI (trajectories). Trajectory analysis models patterns of change over time in the dependent variable and identifies distinct subgroups within the population. Understanding the distinct trajectories of shoulder pain and their determinants offers insight into the development of shoulder pain and in the possible risk factors for chronic shoulder pain, which is prerequisite for early intervention. To our knowledge, there are no studies that empirically identified trajectories of shoulder pain after SCI.

The current study is an extension of an earlier prospective cohort study that addressed shoulder pain in persons with SCI.⁵ The objective of the current study was 1) to identify distinct trajectories of shoulder pain in the period between the start of active SCI inpatient rehabilitation and five years after discharge, and 2) to find determinants of these trajectories.

We hypothesized that four trajectories of shoulder pain would be identified: a stable high, a stable low, a decrease and an increase trajectory. We hypothesized that time since injury (TSI), presence of shoulder pain before SCI, age, gender, lesion characteristics, physical characteristics (BMI, Manual Muscle strength (MMT)), spasticity of the elbow flexors and/or extensors, and limitation in shoulder ROM at the start of active rehabilitation would be determinants of shoulder pain trajectory.

METHODS

The manuscript used the checklist for cohort-studies as provided by the STROBE-statement (STrengthening the Reporting of OBservational studies in Epidemiology) (www.strobe-statement.org).

Participants

Participants with a recently acquired SCI (N=225) were included in the longitudinal Dutch study 'Physical strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of individuals with spinal cord injury'.¹⁹ Participants were admitted to inpatient rehabilitation in one of the eight Dutch rehabilitation centers with a specialized SCI department. Inclusion criteria of the study were: (1) a recently acquired SCI; (2) age between 18 and 65 years; (3) grade A, B, C, or D on the American Spinal Injury Association (ASIA) Impairment Scale (AIS); (4) expected permanent wheelchair dependency for long distances and; (5) having completed a minimum of one outcome assessment on shoulder pain.²⁰ Participants were excluded if they had a SCI due to a malignant tumor, a progressive disease, psychiatric problems, or insufficient command of the Dutch language (necessary for understanding the goal of the study and test instructions).

The research protocol was approved by the Medical Ethics Committees of the SRL/iRv and University Medical Center Utrecht. All persons gave written informed consent to participate in the study.

Study design

A multicenter, prospective cohort study was conducted with measurements taken at the time when a participant was able to sit four or more hours in the wheelchair (t1), three months later (t2), at discharge from inpatient rehabilitation (t3), and one and five years after inpatient rehabilitation (t1 and t5, respectively).

Instruments

All clinical measurements were assessed by trained physicians and research assistants.

Shoulder pain

On all five test occasions (t1–t5), the participants were asked, in a standardized questionnaire, whether they experienced pain on the joints or muscles of both shoulders (since SCI at t1, since last measurement time at t2, t3, t4 and t5). The question to the participants was formulated as follows: “Did you experience pain to your joints or muscles since your spinal cord injury?”. If the question was answered positive, patients were asked to rate the severity of shoulder pain. Severity of musculoskeletal pain was measured for both shoulders on a scale of 0–5 (0=no pain, 1=very mild, 2=mild, 3=moderate, 4=severe, and 5=very severe).⁵

The questionnaire tried to distinguish musculoskeletal pain from neuropathic pain as best as possible by also asking the character of the pain (i.e., pain related to movement in musculoskeletal pain versus other sensations of pain which could be itching or blunt).²¹

Furthermore, participants were asked at the start of active rehabilitation whether they had suffered shoulder pain before SCI. In the analysis, a patient was considered to have shoulder pain if he/she suffered pain in at least one shoulder. In cases where both shoulders were affected, only the shoulder with the highest pain score was included in the analysis.

Lesion characteristics

Level and completeness of SCI were recorded according to the International Standards for Neurological Classification of SCI.²² Tetraplegia was defined as a neurological level of SCI above the T1 segment. SCI was defined as motor complete when participants met the criteria of the International Standards for Neurological Classification of SCI AIS A or B.

Demographics

Age and gender were recorded in the study at the start of active rehabilitation.

Time since injury

For all participants, TSI was determined as the time between the occurrence of SCI and the first measurement time (t1) (noted in months).

Shoulder range of motion

Following a standardized protocol, passive ROM (flexion, external rotation and abduction) of both shoulders was measured in a sitting position²³ using goniometry.²⁴ Normal passive ROM was defined on clinical daily practice: 180° for shoulder flexion, 60° for external rotation

and 90° for glenohumeral abduction. In our study a decrease in ROM of 10° or more in one of the movements was considered to be an impaired ROM. This cut-off point was chosen by physicians working in the field of SCI.

Manual muscle strength

To assess the strength of five muscle groups of the upper extremities, standardized manual muscle testing (MMT)²⁵ was performed for the elbow flexors and extensors, internal and external shoulder rotators, and shoulder abductors. The MMT for each muscle group was performed in a standardized sitting position. However if, the MRC score of shoulder external rotation and internal rotation was scored as MRC grade 3, or for shoulder abduction grade 0,1 or 2 patients were retested in a supine position.²⁵ Muscle force was assessed by the research assistant on a scale of 0–5 as follows: (0) no muscle contraction, (1) palpable or visible muscle contraction, (2) active movement through full range of motion (ROM) with gravity eliminated, (3) active movement through full ROM against gravity, (4) active movement through full ROM against resistance, and (5) normal muscular strength. The muscle group scores of the right and left upper extremities were added together to obtain an overall MMT score, ranging from 0 to 50.

Obesity

A BMI (body mass (kg)/height (m)²) of greater than 22 was used to define overweight or obese; this was defined using the cut-offs for SCI suggested by Laughton et al.²⁶ Mass (in kg) was measured on a wheelchair scale with the patient sitting in the wheelchair or with a weighting lift scale. In the first case, the wheelchair and orthotics of the patient were weighed separately and the mass was subtracted from the first measurement to obtain body mass. Body height was defined in meters according to self-report by participants at t1.²⁷

Spasticity of elbow flexors/extensors

The presence of spasticity of the elbow flexors and extensors of both arms was determined in participants with tetraplegia. Spasticity was defined, based on the definition of Lance et al., as a velocity-dependent increase in muscle tone combined with exaggerated reflexes, through a direct standardized examination (1: catch; 2: clonus <5 beats; 3: clonus ≥5 beats).²⁸ In the analyses, we used a dichotomous variable of spasticity (0 = no spasticity or grade 1, 1 = grade 2 and 3).

Statistical analyses

Respondent characteristics

Descriptive data are displayed as means, SDs, and range or interquartile range. To identify significant differences between the trajectories (demographics, lesion characteristics and physical characteristics), cross-tabulations with chi-square tests were performed for nominal data and one-way ANOVA for numerical data. Non-parametric statistical analyses were used for data that were not normally distributed.

Identifying trajectories

Distinct trajectories of shoulder pain were determined by fitting Latent Class Growth Mixture Models (LCGMM)^{29,30} to the data, using Mplus software.³¹ LCGMM are contemporary statistical techniques based on regression and structural equation models³² and aim to capture heterogeneity in the course of shoulder pain in k number of subgroups (or classes), each with a unique trajectory. Each subgroup has its own growth parameters (e.g. intercept, slope, and variance) and characteristics. In LCGMM, missing data are handled by the Expectation-Maximization-algorithm (EM-algorithm) when they are missing at random. This means that the analysis makes full use of all available data, thereby preventing the inclusion of only those patients that have data on all data points available. This method of data analysis is common in settings where longitudinal data are available; many studies have shown that when the data are missing at random (meaning that missing data are assumed to be unrelated to the outcome variable or that dropout at each occasion is assumed to be conditionally independent of current and future responses on the particular outcome variable, in this study shoulder pain), bias in parameter estimates is avoided. Although the missing data assumptions are difficult to test, we have compared the patients with full availability of the data too on the relevant variable (shoulder pain).³³

To determine the optimal number of trajectories, a common forward procedure was conducted where models with varying number of classes and parameters are assessed and compared.³⁴ To guide the choice for the optimal model, the Bayesian Information Criterion (BIC)³⁵ and the Bootstrapped Likelihood Ratio Test (BLRT),³⁶ two commonly used indices,³⁷ were used to assess model fit. A lower BIC value indicates a better fitting model, while a significant p-value for the BLRT favors the model with k classes over the model with $k-1$ classes. Besides the model fit indices, high posterior probabilities (high probabilities imply distinctive classes) and clinical relevance were taken into account in the modeling process (rejecting clinically uninterpretable classes).^{37, 38} Once the choice for the optimal model

was made, participants were assigned to the trajectory to which they had the highest probability of belonging to.³⁹

Additional sensitivity analyses were conducted by re-running LCGMM using only the data of the patients for which data on shoulder pain was available for all time points.

Predictors of shoulder pain trajectories

Logistic regression models were used to determine which predictors (i.e., TSI, age, gender, lesion characteristics (level and completeness), physical characteristics (presence of shoulder pain before SCI), BMI, MMT, spasticity of the elbow flexors and/or extensors, and limitation in shoulder ROM) could discriminate between the trajectories. First, bivariate logistic regression analyses were conducted to determine which predictors should be included in the multiple logistic regression analyses by using the selection criterion of a p-value less than 0.10. All selected predictors at t1 were then simultaneously entered into the model and backward elimination was used, leading to a final multivariable logistic regression model including only significant predictors.

SPSS statistical program for Windows (version 16.0) was used for testing the group differences and performing regression analyses.

RESULTS

Respondent characteristics

At t1, 225 persons with a newly acquired SCI were included in the study. After 3 months (t2) 155 persons participated, at discharge (t3) 198, one year after discharge (t4) 156, and 131 persons participated 5 years after discharge (t5). The lower number of participants in the second measurement is due to the measurement of 3 months after SCI (t2) not being recorded for those participants with a short duration of inpatient rehabilitation and were instead directly included in the measurement at discharge (t3). At 5 years after discharge (t5) 30 persons had died, 10 could not be contacted, 17 declined to participate in the study anymore, 5 had moved, and the other one dropped out for other reasons.

Participants' characteristics at t1 are displayed in Table 3.1. The median time from injury until admission to the rehabilitation center was 32 days (interquartile range (IQR) 19–54 days). The median time between the onset of SCI and first assessment was 75 days (IQR

Table 3.1 Descriptive characteristics of participants at t1

Characteristics	Participants (N=225)	
	n	%
Male	168	74.7
Type of injury		
Tetraplegia	91	40.4
Motor Complete (AIS A or B)	152	67.6
Neurological level		
C1–C4	21	9.3
C5–Th1	50	22.2
Th2–Th6	48	21.3
Th7–Th12	58	25.7
L1–S4–5	48	21.3
Presence of shoulder pain before SCI (y/n)	21	9.3
Presence of any shoulder pain (y/n)	79	43.1
Presence of bilateral shoulder pain (y/n)	55	24.4
Presence of limitation in shoulder ROM >10° (y/n)	80	35.6
Age (y) (mean, range)	40.7 (18–66)	
BMI (kg/m ²) (mean, range)	22.9 (15.5–35.6)	
MMT sum score (mean, range)	42 (0–50)	
Spasticity of elbow flexors or extensors score (mean, range)	0.25 (0–5)	

Values are n (%), or as otherwise indicated. AIS = ASIA impairment scale; ROM = range of motion; BMI = Body Mass Index; TSI = time since injury; MMT = manual muscle testing; Y = years.

52–115 days). Median duration of rehabilitation in the study population was 225 days (IQR 156–328 days), for persons with a paraplegia median length of stay was 194 (IQR 148–279 days), and for persons with a tetraplegia 293 days (IQR 192–407 days). All 44 persons with a level of SCI C5 or higher had preserved sensory function above, at or below the neurological level of injury.

Identifying trajectories

In the current study a prevalence of musculoskeletal shoulder pain in the total group was found to be 43% at start of active rehabilitation (N=225), 50% 3 months later, 40% at discharge, 34% 1 year after discharge and 42% 5 years after discharge. Shoulder pain trajectories were identified using Latent Class Growth Mixture Modelling. Table 3.2 shows that a model with three shoulder pain trajectories best represented the data (i.e., having the lowest BIC number and a significant p-value of BLRT).

Table 3.2 Criteria for selecting the number of trajectories

Number of trajectories	Bayesian Information Criterion	Bootstrapped likelihood ratio test	Mean posterior probabilities	Entropy
1	1992.61	Not applicable	1	Not applicable
2	1864.121	p<0.001	0.914	0.71
3	1863.248	p<0.001	0.853	0.79
4	1864.09	p<0.001	0.79	0.69

The three trajectories found are: (a) ‘No or Low pain’ (n=148, 64%), (b) ‘High pain’ (n=63, 30%) and (c) a ‘Decrease of pain’, for which pain decreased over time (n=14, 6%).

Additional sensitivity analyses re-running latent class growth mixture on the data of the patients who have data at every time points for shoulder pain (total n=87 patients) yielded similar trajectories, a ‘No or Low pain’ trajectory (n=57 patients; 65%), a ‘High pain’ trajectory (n=27 patients; 31%) and a ‘Decrease of pain’ trajectory (n=3 patients; 4%).

Table 3.3 gives a descriptive overview of the course of shoulder pain (number and percentage of persons having shoulder pain) of the total group as used in Latent Class Growth Mixture Modelling and of the three trajectories with their shoulder pain scores (median, standard deviation) at each measurement time (with their actual n) (Figure 3.1).

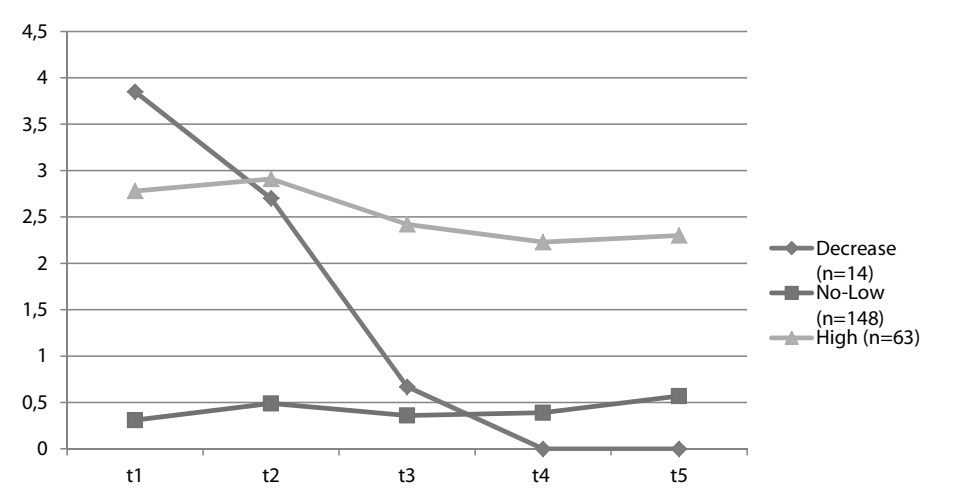


Figure 3.1 Three estimated trajectories in shoulder pain between the start of active rehabilitation and 5 years after discharge from inpatient rehabilitation (N=225).

Table 3.3 The three shoulder pain trajectories, number (%) of participants with pain at the measurement times and shoulder pain scores (mean, standard deviation); range of pain score 0–5

	n*		Start active rehabilitation (N=225)	3 months after start rehabilitation (N=155)	Discharge (N=198)	1 year after rehabilitation (N=156)	5 years after rehabilitation (N=131)
Total group	225	N with pain (%)	97 (43)	77 (50)	78 (40)	53 (34)	59 (42)
High pain	63(28)	N with pain (%)	26 (41)	23 (73)	25 (78)	22 (49)	27 (51)
		Mean pain score	2.78 (1.32)	2.92 (1.37)	2.23 (1.45)	2.15 (1.55)	2.18 (1.55)
Decrease of pain	14(6)	N with pain (%)	14 (100)	8 (57)	4 (29)	0	0
		Mean pain score	3.86 (0.36)	2.36 (1.75)	0.46 (0.87)	0	0
No or Low pain	148(66)	N with pain (%)	57 (39)	46 (16)	49 (17)	31 (14)	32 (18)
		Mean pain score	0.25 (0.66)	0.42 (0.91)	0.32 (0.80)	0.35 (0.84)	0.55 (1.03)

* Total n used in Latent Class Growth Mixture Modeling.

Table 3.4 Characteristics per shoulder pain trajectory measured at start of active rehabilitation (t1) (N=225) and significant differences between trajectories (described in n and % per trajectory)

	Descriptives			P-values of differences between trajectories		
	High pain (n=63)	Decrease of pain (n=14)	No or Low pain (n=148)	High pain vs. Decrease of pain	High pain vs. No or Low pain	Decrease of pain vs. No or Low pain
Demographics						
Male	44 (70%)	13 (93%)	111 (74%)	0.067	0.270	0.114
Female	19 (30%)	1 (7%)	37 (26%)			
Age (y)	40.4 (13.7)	32.6 (12.0)	41.7 (14.4)	0.195	1.00	0.068
TSI (days)	107 (72)	100 (40)	92 (75)	0.516	0.086	0.033
Lesion characteristics						
Paraplegia	21 (33%)	3 (21%)	110 (74%)	0.298	<0.001	<0.001
Tetraplegia	42 (67%)	11 (79%)	38 (26%)			
Complete	45 (71%)	11 (79%)	96 (65%)	0.430	0.283	0.267
Incomplete	18 (29%)	3 (21%)	49 (35%)			
Physical characteristics						
Presence of shoulder pain before SCI	10 (16%)	2 (14%)	9 (6%)	0.287	<0.001	<0.001
Presence of obesity (BMI≥22)	34 (50%)	2 (14%)	86 (58%)	0.012	0.219	0.002
Presence of limitation in shoulder ROM of >10°	41 (60%)	8 (57%)	31 (21%)	0.547	<0.001	0.004
MMT score (range 0-50)	36.6 (13.1)	33.3 (10.3)	45.4 (9.4)	0.011	<0.001	<0.001
Spasticity of elbow flexors or extensors score (range 0-3)	0.54 (1.18)	0.33 (0.65)	0.10 (0.47)	<0.001	<0.001	0.982

For sex, lesion level, completeness of SCI, presence of shoulder pain before SCI, presence of obesity presence of shoulder ROM limitation, values are n (and %) per trajectory. For age, TSI, MMT and spasticity the mean (and standard deviation) is described. All variables were measured at the start of active rehabilitation. Significance was set at p<0.001. TSI = time since injury; BMI = Body Mass Index; ROM = range of motion; MMT = manual muscle testing.

Predictors of shoulder pain trajectories

The 'High pain' trajectory, compared to the 'No or Low pain' trajectory, was characterized by having more persons with tetraplegia, more persons with shoulder pain before the SCI, a limited shoulder ROM, lower MMT and more spasticity at t1. The group with the 'High pain' trajectory compared to the 'Decrease of pain' trajectory showed to be more often obese, have a slightly higher MMT score and suffer from more severe spasticity at t1. The 'Decrease of pain' trajectory compared to the 'No or Low pain' trajectory was characterized by having fewer persons with a paraplegia, more persons with shoulder pain before SCI, fewer obese persons, more shoulder ROM limitations and a lower MMT at t1. The p-values are displayed in the Table 3.4.

The results of the multiple backward logistic regression analyses show that lesion level and a presence or absence of a shoulder ROM limitation at t1 distinguishes between the 'High pain' and 'No or Low pain' trajectories (Nagelkerke's R^2 : 0.243). Persons with tetraplegia (OR=2.8) and those with a limited shoulder ROM (OR=3.6) were more likely to belong to the 'High pain' trajectory. The results of the multiple backward regression analyses, including Beta, Standard Error, 95% Confidence Interval and p-values are displayed in Table 3.5.

Because the 'Decrease of pain' trajectory was only comprised of 14 persons, no multiple statistical analyses were performed on this group.

Table 3.5 Outcome of multiple logistic regression analyses

	B	Outcome of logistic regression analyses			
		S.E.	OR	95% CI	P
Constant	-0.481	0.359			
Lesion characteristics					
Lesion level (paraplegia)	-1.163	0.382	0.312	-1.912/-0.414	0.002
Physical characteristics					
Presence of limitation in shoulder ROM of >10°	1.037	0.382	2.820	0.228/1.786	0.007

DISCUSSION

The current study is, to our knowledge, the largest study in which shoulder pain in persons with SCI was examined over a time period from start of active rehabilitation until 5 years after discharge. It is also the first study that identified distinct trajectories of musculoskeletal

shoulder pain in SCI using LCGMM, thus giving more insight into subgroup patterns on shoulder pain in time.

Limitations

In the study, persons with SCI between 18 and 65 years and with expected permanent wheelchair dependency admitted to a rehabilitation center were included. Persons that were mainly walking (with or without aids) or expected to do so were not included in the study. This influences the representativeness of the population and thereby the degree to which the results of our study can be generalized to the whole population of persons with SCI (e.g., persons that are able to walk).

The assessment of pain in persons with SCI is difficult. It is difficult to distinguish between neuropathic pain from musculoskeletal pain, especially among persons with a level of SCI of C5 and higher. Shoulder pain typically presents in dermatome C5. In 21 cases the sensory level of injury was diagnosed at t1 at C4 or higher. All persons with a sensory level of C4 or higher had preserved sensation above, at or below the neurological level. In the questionnaire we tried to distinguish neuropathic pain from musculoskeletal pain by asking the character of pain. However, we cannot completely rule out that some persons could not clearly distinguish between neuropathic pain and musculoskeletal pain.

Body height was defined in meters according to self-report by participants at t1. One could argue that self-reported height might not be the best way to record height. The study of Froehlich-Grobe et al. concluded: "Recumbent length yields the most accurate height estimate for wheelchair users. However, when logistical and practical considerations pose difficulties for obtaining this measure, height estimates based on knee height and self-report may provide reasonable alternatives."²⁷ For our study hypothesis we felt self-reported height was acceptable.

Although we had the largest SCI cohort population to study shoulder pain to-date, some persons were lost to follow-up. For the LCGMM, missing data were handled according to the Expectation-Maximization Algorithm (EM-Algorithm). Although statistically sound, this algorithm assumes data to be missing at random. This assumption is unfortunately difficult to test and we therefore cannot rule out that the group lost to follow is 'not random' and could have influenced our outcomes. However, a sensitivity analysis found no clear indications that this was the case.

Identifying trajectories

Based on data of 225 persons with SCI, three distinct musculoskeletal shoulder pain trajectories were identified in the period between the start of active SCI rehabilitation and five years after discharge: a 'High pain' trajectory, a 'No or Low pain' trajectory and a 'Decrease of pain' trajectory. We hypothesized that we would also identify a fourth trajectory with an increase of shoulder pain. Both the 'High pain' and 'No or Low pain' trajectory showed a slight tendency for increase in musculoskeletal shoulder pain between 1 and 5 years after discharge (t4 and t5, respectively), but no distinct 'Increase' trajectory could be identified. We assume that the follow-up time of 5 years after discharge is too short to show pain problems in the shoulders due to overuse, especially in paraplegics, which might occur later.

In the current study, a prevalence of musculoskeletal shoulder pain in the total group was found to be 43% at start of active rehabilitation, 50% 3 months later, 40% at discharge, 34% 1 year after discharge and 42% 5 years after discharge. This is lower than prevalence of shoulder pain in the literature on persons with chronic SCI, which is found to be between 60% and 89%.^{2, 4, 12, 14, 15, 40} Unfortunately, these studies mostly do have a cross-sectional study design, use a different definition of shoulder pain (distinguish musculoskeletal and neuropathic pain) and use different outcome measures and/or include different populations and TSI. Therefore, comparison with prevalence of shoulder pain in our study should be interpreted with caution.

One prospective cohort study by Salisbury et al., was conducted in 41 persons with a tetraplegia during first inpatient rehabilitation with a follow-up after 2 and 4 years.^{11, 18} They showed that shoulder pain was present during inpatient rehabilitation in 85% of the patients. In our study the 'High' shoulder pain trajectory showed similar prevalence (90% at t1, 73% at t2, and 78% at t3). After 4 years Salisbury et al. found a shoulder pain prevalence of 70%, which is higher compared to what was found after 5 years in our study population (51%). The higher percentage compared to our study is probably due to the fact that Salisbury et al included only persons with a tetraplegia (n=41),^{11, 18} while one third of our 'High' group consisted of persons with paraplegia.

Predictors of shoulder pain trajectories

Although significant differences between the three trajectories exist by group characteristics using bivariate analysis (Table 3.4), based on multivariable logistic regression our current study identified two significant predictors of belonging to the 'High pain' trajectory (as compared to the 'No or Low pain' trajectory): 1) having a tetraplegia and 2) having a limited shoulder ROM.

The other included factors that were expected to be possible predictors for belonging to a distinct (High pain and No or Low pain) trajectory (age, TSI, completeness of the injury, presence of shoulder pain before SCI, obesity and spasticity) were, not revealed as significant in the final multiple logistic regression analyses. In the literature different variables associated with shoulder pain in SCI have been described. In recently published studies older age,¹⁸ longer time since injury (TSI), higher BMI,^{5,13,14} lesion level (tetraplegia),⁵ muscle strength (inversely related),⁵ longer duration of bed rest¹⁸ and functional outcome (inversely related)^{5,15} were related to higher shoulder pain scores. However, as aforementioned, most of above described findings are based on studies with in persons with chronic SCI using a cross-sectional design, and should therefore be interpreted with caution.

The 'Decrease of pain' trajectory only existed of 14 persons, and was therefore was not included in the multiple analyses. In the bivariate analysis, the 'Decrease of pain' trajectory was not to be significantly different from the 'High pain' trajectory with regard to level of injury and shoulder ROM, but were significant more obese, had a lower MMT score and suffer more frequent from spasticity.

Although we hypothesized an 'Increase of pain' trajectory we did not find it in the analysis; this is probably due to the limited follow-up time of the study. The 'High pain' shoulder pain trajectory consists of mainly persons with a tetraplegia. People with a SCI might develop overuse issues in the shoulders and shoulder pain at a later stage, especially persons with a paraplegia. In the current study we did not study the causes of shoulder pain by clinical exam or radio diagnostics. Adding this in future studied would give us better insight on the potentially different patho-physiological mechanisms of shoulder pain among persons with tetraplegia and paraplegia.

Future directions

Although our results suggest a likely causal relationship, one should test our findings with other datasets of persons with SCI to confirm this relationship.

Larger studies are needed to be able to show relevant associations of, for example, lesion level within the paraplegic group (high paraplegics versus low paraplegics), and to study the role of posture and trunk stability on the development of shoulder pain.

The duration of the current study was up to 5 years after inpatient rehabilitation. Two trajectories show a tendency of increase from 1 to 5 years after SCI. To show whether this increase is relevant, and might retrieve a fourth 'Increase of pain' trajectory a follow-up

measurement at, for example, 10 years is needed. Adding clinical testing, radio diagnostics and kinematics would be key to understanding the mechanism of shoulder pain in the various trajectories. Studies should also include the assessment of postural control. Persons with SCI have shown to make use of non-postural muscles to maintain their sitting balance.⁴¹⁻⁴⁵ Whether these adaptations in postural control are associated with the development of shoulder pain so far has not been studied.

It was beyond the scope of this study to include all interventions for the reduction of shoulder pain. Assessment of interventions is needed in order to open the 'black box'. Current initiatives such as the SCIR rehab project⁴⁶⁻⁵⁰ and the Spinal Cord Injury-International Classification System⁵¹⁻⁵⁵ have now provided us with the possibility to open this 'black box', at least to some extent.

Future intervention studies for treatment and/or prevention should include a large, homogeneous study population, should have a long duration of follow-up time, and should include, if possible, a control group. Interesting would be to study the effects of earlier shoulder mobilization starting early after SCI by specialized physiotherapists paying attention not only on shoulder external rotation and abduction, but also to preserve shoulder flexion by for example scapula stabilization and mobilization⁵⁶ and balanced muscle training.

In summary, the results of the current study and (lack of) available evidence show that there is a need for longitudinal studies with longer follow-up time, comprehensively studying the course over time of shoulder pain and studying the effect of interventions, such as early mobilization and early muscle strength training, on shoulder pain in persons with SCI.

Clinical implications

Our findings show that shoulder pain is a frequent problem, even in patients that have a SCI for 'only' approximately 5 years. Health professionals should be aware of the increased risk of belonging to the 'High pain' trajectory in persons with tetraplegia and those with a limited shoulder ROM. In a former study, in the same cohort, on shoulder ROM limitations in persons with SCI, it was shown that especially shoulder flexion was limited.¹⁶ Prevention of shoulder problems should be a main goal of rehabilitation. Using guidelines such as the guideline for 'Preservation of Upper Limb Function Following Spinal Cord Injury' or the 'Guidelines for the prescription of a seated wheelchair or mobility scooter for people with a traumatic brain injury or spinal cord injury' (Download: <http://www.enable.health.nsw.gov.au/publications> or LTCSA; <http://www.lifetimecare.nsw.gov.au/Resources.aspx>) could

be helpful in structuring treatment and preventive interventions of shoulder problems in persons with SCI.⁵⁷ Furthermore, wheelchair propulsion has been shown to be straining and to place a high load on the shoulder,⁵⁸⁻⁶² thereby increasing the risk of structural changes and the development of shoulder pain. Alternative propulsion modes, such as hand cycling for mobility and exercise, instead of hand-rim wheelchair propulsion, should be considered by clinicians at an early stage.^{58, 63, 64}

CONCLUSION

This study confirmed that shoulder pain is a problem in the SCI population during, and after inpatient rehabilitation, with a prevalence of 43% 5 years after discharge from inpatient rehabilitation.

In the current study we unraveled some of the complexity of musculoskeletal shoulder pain, showing different trajectories of shoulder pain and their predictors on basis of a longitudinal data set.

Three distinct musculoskeletal shoulder pain trajectories in persons with acute SCI exist; a 'High pain' trajectory, a 'Decrease of pain' trajectory, and a 'No or Low pain' trajectory.

Having a tetraplegia and having a limited shoulder ROM at the beginning of active rehabilitation increases the risk of belonging to the 'High pain' trajectory, and therefore special attention should be paid to these persons. Monitoring shoulder pain at the start of active rehabilitation might allow identification of persons at risk for poor long-term outcomes.

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Chapter 4

Passive shoulder range of motion impairments

in people with a spinal cord injury

during and one year after
rehabilitation

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Passive shoulder range of motion impairment in spinal cord injury during and one year after rehabilitation.
J Rehabil Med 2009; 41(6): 438-44. (modified, publication with permission)

ABSTRACT

Objective: To investigate the prevalence and course of passive shoulder range of motion (ROM) in people with a spinal cord injury (SCI) and the relationships between shoulder ROM limitations and personal and lesion characteristics.

Design: Multicenter longitudinal study.

Subjects: 199 subjects with SCI admitted to specialized rehabilitation centers.

Methods: Assessments of shoulder ROM at the start of active rehabilitation, 3 months later, at discharge and 1 year after discharge.

Results: Up to 70% (95% CI: 57–81) of the subjects with tetraplegia and 29% (95% CI: 20–38) of those with paraplegia experienced a limited shoulder ROM during or in the first year after inpatient rehabilitation. Shoulder flexion was mostly affected. Up to 26% (95% CI: 20–37) of the subjects had a shoulder ROM limitation on both sides. Increased age, tetraplegia, spasticity of elbow extensors and longer duration between injury and start of active rehabilitation increased the risk. Presence of shoulder pain is associated with limited shoulder ROM.

Conclusion: Limited shoulder ROM is common following SCI. Tetraplegia, increased age, spasticity of elbow extensors, longer duration between injury and start of active rehabilitation and shoulder pain are associated with an increased risk for shoulder ROM problems and require extra attention.

INTRODUCTION

An unlimited range of motion (ROM) of the shoulder is needed for different tasks in daily life like, for example, reaching, and perineal care. Shoulder ROM limitations may therefore lead to dependence upon help from others for those activities.^{1,2}

People with spinal cord injury (SCI) highly depend on the function of their upper limbs for mobility and ADL and are more than people without SCI at risk for over-use shoulder problems.³ During rehabilitation, a decreased shoulder ROM may limit participation in rehabilitation activities and thereby delay rehabilitation or lead to sub-optimal outcomes.

Most studies on shoulder problems in SCI addressed shoulder pain.⁴⁻¹² Few studies focused on shoulder ROM^{13, 14} or the relationship between shoulder ROM and shoulder pain.⁶ A study in 89 men with SCI living in the community showed that 22% reported shoulder ROM problems and relationships with level and completeness of the lesion, age, shoulder pain and functional independence scores were found.¹³ Another study in 41 patients with tetraplegia⁶ showed that, during rehabilitation, patients with shoulder pain lost ROM in flexion, abduction, and external rotation at 90° abduction. The latter finding was only significant for abduction at the left side. A loss of shoulder ROM was significantly related to previous shoulder injury on admission.⁶ A cross-sectional study in 352 subjects having a tetraplegia for longer than 20 years showed that 12% had upper-extremity joint problems, enfolded in shoulder and non-shoulder problems. Women and those with longer time since injury reported more upper extremity problems than men.¹⁴

These studies however had several limitations, hampering understanding of the prevalence and course of shoulder ROM in people with SCI. They were mostly performed in chronic SCI, had a cross-sectional design or were relatively small. Also, shoulder ROM and shoulder problems were not clearly defined.

To gain understanding of limitations in shoulder ROM in people with SCI during and after rehabilitation as well as relations between shoulder ROM and personal and lesion characteristics, spasticity of elbow flexors and extensors, shoulder pain and time since injury at start of active rehabilitation, we assessed shoulder ROM (flexion, external rotation, abduction) in a prospective cohort study with the following research questions:

1. What is the prevalence of shoulder ROM limitations in subjects with SCI at standardized time points during inpatient rehabilitation and the first year after discharge?
2. What is the course of shoulder ROM limitations in people with SCI during inpatient rehabilitation and the first year after discharge?

3. What are the relationships between limitations in shoulder ROM and personal characteristics (age and gender), lesion characteristics (level, completeness of the lesion), time since injury, spasticity of elbow flexors and extensors and shoulder pain?

METHODS

Subjects

The present study was part of the Dutch research program 'Physical strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of persons with SCI'. Subjects, after having received acute care in an academic or a large general hospital, admitted to the SCI unit of one of 8 participating rehabilitation centers between May 2000 and September 2003 were included if they met the eligibility criteria: acute SCI, classified as A, B, C or D on the American Spinal Injury Association (ASIA) impairment scale,¹⁵ between 18 and 65 years of age, wheelchair dependence (using a wheelchair for daily mobility), sufficient comprehension of the Dutch language to understand the purpose of the study and not having a progressive or psychiatric condition that could interfere with constructive participation.¹⁶

Procedure

Measurements were conducted following a standardized protocol by a trained research assistant at the start of active inpatient rehabilitation (t1) (defined as the moment when the subject was able to sit in a wheelchair ≥ 3 hours), 3 months later (t2), at discharge of inpatient rehabilitation (t3) and 1 year after discharge (t4). If the subject was discharged within one month after t2, the assessment at t2 was considered the 'discharge' measurement, and was included in the analyses as t3.

All subjects gave their written informed consent prior to the study, which was approved by the Medical Ethics Committee of the Stichting Revalidatie Limburg and the Institute for Rehabilitation Research and by all local Medical Ethics committees.

Instruments

ROM

Following a standardized protocol, passive ROM of both shoulders was measured in sitting position for flexion, external rotation and abduction, using goniometry.¹⁵ Passive normal

ROM was defined by physicians working in the field of SCI as: 180° for shoulder flexion, 60° for external rotation and 90° for glenohumeral abduction.

A decrease of ROM of 10° or more was considered to be an impaired ROM. This cut-off point was chosen by experts working in the field of SCI.

Personal and lesion characteristics

Age and gender of all subjects were recorded at t1. Level and completeness of the lesion were recorded at each measurement according to the ASIA classification.¹⁶ Tetraplegia was defined as a lesion at or above the T1 segment. A lesion was defined motor complete when subjects met the criteria of the ASIA Impairment Scale A or B.

Time since injury

For all subjects, time since injury (TSI) was determined as the time between the occurrence of SCI and t1 (in days) and called TSI_{t1}.

Spasticity

The presence of spasticity of the elbow flexors and extensors of both arms was determined in subjects with tetraplegia. Spasticity was defined as the velocity-dependent increase in muscle tone combined with exaggerated reflexes, through a direct standardized examination (1: catch; 2: clonus <5 beats; 3: clonus ≥5 beats).¹⁵

Musculoskeletal pain

Subjects were asked in a standardized questionnaire if they experienced pain in the shoulder joint or muscles around the shoulder (for details see Van Drongelen et al.⁵). At t1, subjects were asked about shoulder pain since the time of injury. At t2, t3 and t4, subjects were asked if they experienced pain since the previous measurement (no pain = 0, presence of pain = 1).

Statistical analysis

Firstly, Shoulder ROM was measured and prevalence of impaired shoulder ROM was calculated at each measurement. Changes in prevalence of impaired shoulder ROM between t1 and t3 were calculated in the total group and in subjects with paraplegia and tetraplegia separately. These calculations were also performed for the changes in prevalence between t3 and t4. Furthermore, prevalence of limited shoulder ROM in one or both shoulders was calculated during and after rehabilitation.

Secondly, to determine whether the occurrence of impaired shoulder ROM significantly changed over time, the multilevel modelling program MLwiN (MLwiN version 1.1; Centre for Multilevel Modelling, Institute of Education, London, UK) was used.¹⁷ In the longitudinal data set of this study, the hierarchy in the data is the repeated measurement 'test occasion (t1–t4)' (level 1), which is grouped within the individual subjects (level 2), who are grouped in the rehabilitation centers (level 3). Limitations in shoulder ROM (no limitation = 0 and limitation = 1) for left and right side and each of the three movement direction separately, were the dependent variables in a multilevel binomial regression analysis. Time was modelled with three categorical dummy variables, with t3 as the reference to t1, t2 and t4. The regression coefficient for a time dummy describes the change in shoulder ROM limitations over that time period. To investigate also the change of shoulder ROM limitations during the first three months of active rehabilitation (t1t2), the regression analysis was also performed with t1 as reference. The regression coefficients were converted to odds ratios (OR). An OR of 1 indicated that there was no association with this particular variable whereas an OR >1 indicated an increased risk of having limited shoulder ROM and an OR <1 indicated a decreased risk of a limited shoulder ROM in the presence of this risk factor. The robustness of our model was tested by analyzing the course over time in those subjects with complete measurement data at t3 and t4.

Thirdly, to investigate the association of shoulder ROM limitations with personal characteristics (age, gender (men = 0; women = 1)), lesion characteristics (paraplegia = 1 and tetraplegia = 0; incomplete = 0; complete = 1), TSlt1 (days), shoulder pain (yes = 1; no = 0) and spasticity of the elbow flexors and extensors (yes = 1; no = 0), were added to the model as independent variables. All variables were added one by one to the basic model with the time dummies only. Independent variables with p-values <0.1 were included in a subsequent multivariate model where a backward selection procedure was followed, excluding non-significant determinants ($p > 0.05$), in order to create the final multivariate model. The regression coefficient for all factors were converted to odds ratios (OR) as explained above. All models were made for shoulder flexion, external rotation and abduction and for the right and left shoulder separately.

RESULTS

Descriptives

At t1 199 subjects were included in the study. Mean age was 40.8 ± 14.1 years. 74% of the included subjects were male, 59% had paraplegia and 45% had a motor complete SCI.

Overall, 48 subjects were lost to follow-up due to several reasons.¹⁸ At t1 the median TSI was 87 days with a minimum of 20 days and a maximum of 448 days.

Prevalence of limited ROM and residual ROM

A limitation in shoulder ROM was present in up to 39% (95% CI: 31–46) of all subjects at start of active rehabilitation (t1) and 23% (95% CI: 16–30) one year after rehabilitation (t4). For subjects with a tetraplegia much higher prevalences were found and for subjects with a paraplegia lower prevalences as shown in Figure 4.1.

Table 4.1 shows the percentages of subjects with limited shoulder flexion, external rotation and abduction at t1, t3 and t4 and the residual ROM. This shows that shoulder flexion is affected most.

Figure 4.2 shows the percentages of subjects without shoulder ROM limitation, shoulder ROM limitation of one shoulder or of both shoulders at t1, t3 and t4.

Course of limitations in shoulder ROM over time

Table 4.2 shows the ORs of all shoulder ROM limitations at t1, t2, t4 compared to t3. No differences in risk of ROM limitations were found between t1 and t2 (Left: flexion: OR=1.0, $p=0.1$, external rotation: OR=0.9, $p=0.8$, abduction: OR=0.9, $p=0.8$, Right: flexion: OR=1.1, $p=0.8$, external rotation: OR=1.8, $p=0.1$, abduction: OR=1.0, $p=0.9$). Multilevel random coefficient analyses revealed that in our study population at the start of active rehabilitation (t1) the chance of having impaired shoulder external rotation or abduction is for the left shoulder 2.2 times higher than at discharge ($p<0.05$). Three months after start of active rehabilitation, we found a 2.6 time higher chance of having an impaired shoulder external rotation for the right shoulder compared to time at discharge. One year after discharge a significant decreased chance of having an impaired shoulder flexion was found compared to discharge. For the right shoulder an OR of 0.5 was found, meaning a 2 times lower chance of limited ROM (Table 4.2).

The results of testing the robustness of our model by including only participants with complete measurement data in t3 and t4 showed no different outcomes compared to the models in Table 4.2.

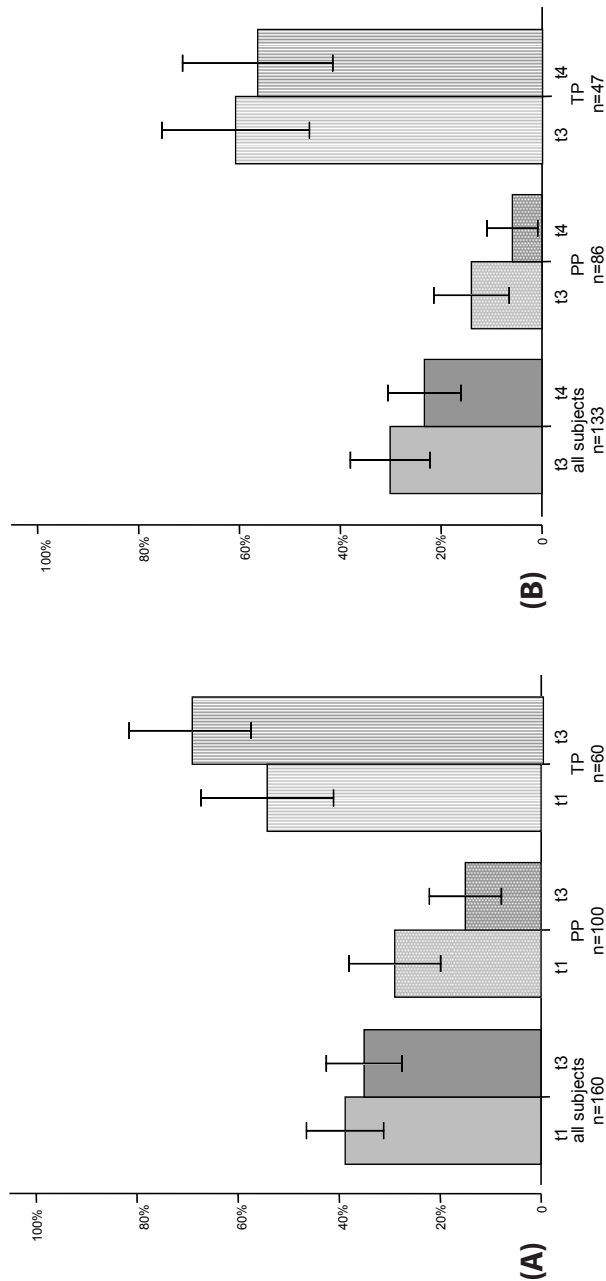


Figure 4.1 Percentage (and 95% CI) of subjects with a shoulder range of motion (ROM) limitation in the overall group, in subjects with paraplegia (PP) and subjects with tetraplegia (TP). **(A)** percentages of subjects with complete measurement datasets at start of active rehabilitation (t1) and at discharge (t3), and **(B)** percentages of subjects with complete datasets at discharge (t3) and at 1 year after rehabilitation (t4).

Table 4.1 Percentage of subjects with complete measurement datasets at start of active rehabilitation (t1) and at discharge (t3) and at discharge (t3) and at 1 year after discharge (t4) with limited shoulder range of motion (ROM)(%limit) in flexion, external rotation or abduction. Normal ROM defined as 180° (flexion), 60° (external rotation), 90° (abduction). Of subjects with a limited ROM mean residual ROM (in degrees) is noticed with their standard deviation (SD) and range.

	Start active rehabilitation-discharge n=160						Discharge-1 year after discharge n=133					
	t1			t3			t3			t4		
	% limit.	Mean (SD)	Range	% limit.	Mean (SD)	Range	% limit.	Mean (SD)	Range	% limit.	Mean (SD)	Range
Flexion												
Right	29	119° (34°)	10–165	26	130° (36°)	20–170	23	127° (42°)	10–170	18	139° (30°)	80–170
Left	33	118° (32°)	30–170	28	134° (36°)	20–170	22	135° (40°)	20–170	16	144° (26°)	80–170
External rotation												
Right	18	25° (16°)	0–50	14	28° (18°)	0–50	12	31° (16°)	0–50	5	37° (28°)	0–50
Left	23	31° (19°)	0–50	15	32° (18°)	0–50	12	37° (13°)	10–50	8	36° (14°)	15–50
Abduction												
Right	8	73° (18°)	40–80	7	76° (8°)	60–80	5	72° (16°)	45–80	5	74° (5°)	70–80
Left	12	74° (13°)	45–80	6	72° (8°)	65–80	2	78° (10°)	70–80	1	80° (0°)	80

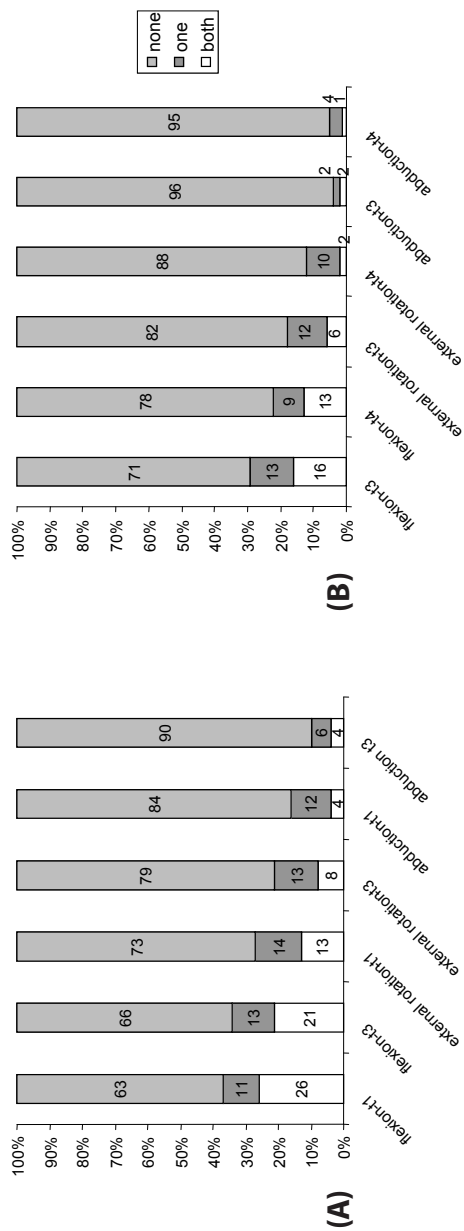


Figure 4.2 Percentage of subjects without limitations in shoulder range of motion (ROM), limitations in one shoulder and limitations in both shoulders. **(A)** percentages of subjects with complete measurement datasets at start of active rehabilitation (t1) and at discharge (t3), and **(B)** percentages of subjects with complete datasets at discharge (t3) and at 1 year after rehabilitation (t4).

Table 4.2 Course of limitations in shoulder range of motion (ROM) as calculated with random coefficient analysis. Shown are the odds ratios (OR) and their 95% confidence intervals (95% CI) of having shoulder ROM limitations at t1, t2, t4 compared to t3.

	Flexion			External rotation			Abduction		
	β	OR	95% CI	β	OR	95% CI	β	OR	95% CI
RIGHT									
Cons	-1.8			-2.989			-2.886		
$\Delta t1t3$	0.396	1.4	0.77–2.03	0.597	1.8	1.03–2.57	0.42	1.4	0.69–2.31
$\Delta t2t3$	0.574	1.8	1.14–2.46	0.962	2.6 [§]	1.83–4.54	0.513	1.8	0.77–2.43
$\Delta t4t3$	-0.684	0.5	-0.26–1.26	-0.96	0.4	-2.31–0.69	-0.398	0.5	-0.32–1.72
LEFT									
Cons	-1.517			-3.181			-2.844		
$\Delta t1t3$	0.498	1.6	0.99–2.21	0.805	2.2	1.38–3.52	0.768	1.6	1.44–2.96
$\Delta t2t3$	0.449	1.6	0.96–2.24	0.683	2.0	1.16–2.95	0.667	1.6	0.90–2.50
$\Delta t4t3$	-0.99	0.4	-0.37–1.17	-0.74	0.5	-1.74–0.51	-1.487	0.4	-1.33–1.73

Relationship with personal & lesion characteristics, TSI, spasticity of elbow flexors, spasticity of elbow extensors and shoulder pain

Table 4.3 shows the relationship between limitations in shoulder ROM and age, gender, level of injury, completeness, TSI at t1, spasticity of elbow flexors, spasticity of elbow extensors and shoulder pain. When different results were found for the right and the left shoulder these were described in the text. In Table 4.3 the OR for age was calculated with an increase of 1 year and for TSI at t1 for every day. For clinical understanding, we described the OR for age with every increase of 10 years of age and TSI with every month (30 days).

Shoulder flexion

Subjects with tetraplegia, an older age, longer duration until start of active rehabilitation (TSIt1) and shoulder pain are at risk for having a limited shoulder flexion. With every increase of 10 years of age the chance of having a limited shoulder flexion is 1.8 times higher for the right and 1.6 times for the left shoulder. This means that a 50 year old subject has a 1.8 (resp. 1.6) times higher chance of developing a limited shoulder flexion compared to a 40 year old subject. TSI at t1 showed to be a risk factor for limited shoulder flexion for both shoulders. Every month delay of active rehabilitation increases the chance of having shoulder flexion problems with 1.3 for the right and 1.5 for the left shoulder. For the left shoulder only, spasticity of elbow extensors increases the chance of having limitations of

Table 4.3 Odds ratios and their 95% confidence intervals (95% CI) for the association with personal and lesion characteristics, TSlt1, spasticity of elbow flexors, spasticity of elbow extensors and pain after random coefficient analysis

	Flexion			External rotation			Abduction		
	β	95% CI	OR	β	95% CI	OR	β	95% CI	OR
RIGHT									
Cons	-7.102			-3.769			-7.122		
$\Delta t1t3$	0.352	0.66–2.14	1.4	0.725	1.41–2.79	2.1	0.550	0.78–2.62	1.7
$\Delta t2t3$	0.312	0.63–2.17	1.4	0.702	1.31–2.69	2.0	0.351	0.48–2.32	1.4
$\Delta t4t3$	-0.527	0.82–2.58	1.7	-0.428	0.58–2.42	1.5	-0.114	-0.05–2.25	1.1
Age	0.059	1.77–1.83	1.8*	n.s.		n.s.	0.052	1.77–1.83	1.8*
Gender	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.
Level	2.319	9.36–11.04	10.2	1.504	3.90–5.10	4.5	1.847	5.40–7.20	6.3
Compl.	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.
TSlt1	0.010	1.29–1.31	1.3**	n.s.		n.s.	n.s.		n.s.
Spasticity flexors	1.562	3.49–6.11	4.8	n.s.		n.s.	n.s.		n.s.
Spasticity extensors	n.s.		n.s.	0.925	1.63–3.37	2.5	1.334	2.70–4.90	3.8
Pain	1.829	5.54–6.68	6.2	1.311	3.16–4.24	3.7	1.512	3.74–5.26	4.5
LEFT									
Cons	-7.152			-7.152			-6.686		
$\Delta t1t3$	0.315	0.63–2.17	1.4	0.559	1.02–2.38	1.7	0.558	0.82–2.58	1.7
$\Delta t2t3$	0.087	0.29–1.91	1.1	0.329	0.71–2.09	1.4	0.506	0.82–2.58	1.7
$\Delta t4t3$	-1.130	2.02–3.98	3.0	-0.264	0.46–2.14	1.3	-2.015	5.37–9.36	7.5
Age	0.050	1.57–1.63	1.6*	n.s.		n.s.	0.044	1.57–1.63	1.6*
Gender	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.
Level	2.477	10.99–12.81	11.9[§]	1.246	2.87–4.13	3.5	0.854	1.53–3.07	2.3
Compl.	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.
TSlt1	0.013	1.49–1.51	1.5**	n.s.		n.s.	n.s.		n.s.
Spasticity flexors	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.
Spasticity extensors	1.206	2.08–4.52	3.3	1.074	2.04–3.76	2.9	1.388	3.07–4.93	4.0
Pain	2.479	11.02–12.68	11.9	1.354	3.24–4.36	3.8	1.886	3.81–7.39	6.6

β = regression coefficient for each independent variable; 95% CI = 95% confidence interval; OR = odds ratio; t1 = start of active rehabilitation; t2 = 3 months after start of active rehabilitation; t3 = at discharge; t4 = 1 year after discharge; $\Delta t1t3$ = t1 compared to t3; $\Delta t2t3$ = t2 compared to t3; $\Delta t4t3$ = t4 compared to t3; Compl. = completeness of the lesion; TSlt1 = duration of bed rest at t1; ns = not significant. * The OR for age for a period of 10 years. ** The OR for TSI for period of one month. [§] Example: Having a tetraplegia was associated with a 11.9 times higher risk of having shoulder flexion limitations.

shoulder flexion. For the right shoulder only spasticity of the elbow flexors increases the chance of limited shoulder ROM.

Shoulder external rotation

Having tetraplegia, spasticity of elbow extensors and presence of shoulder pain was associated with a higher chance of having a limited shoulder external rotation. For example, subjects with pain of the left shoulder had a 3.8 times higher chance of having a limited shoulder external rotation.

Shoulder abduction

Older age, tetraplegia, spasticity of elbow extensors and presence of shoulder pain were associated with shoulder abduction limitations for both shoulders. With every increase in age of 10 years the chance of having limited shoulder abduction rises to 1.8 for the right and 1.6 times for the left shoulder.

DISCUSSION

Prevalence of limited ROM and residual ROM

Shoulder ROM limitations are present in a significant part of the subjects with a SCI in our study. Especially for those subjects with tetraplegia high prevalences were found during and after inpatient rehabilitation. Comparison of our results with the studies of Salisbury et al.^{6,7} and Ballinger et al.¹³ should be made with caution due to inclusion criteria of the study sample (e.g. only wheelchair-dependent subjects). A study by Sinnott et al.¹⁹ in persons with long-term paraplegia showed that 82% of the 22 persons with a T2 to T7 lesion and 40% of the 20 persons with a T8 to T12 lesion were diagnosed with rotator cuff disorders. Ballinger et al.¹³ found ROM problems in 22% of a group of 89 men with long-term traumatic SCI (45% paraplegia, TSI: average 10 years, range 1–48 years).

In our study, we showed that especially shoulder flexion has been affected, at t1 in even up to 26% (95% CI: 20–37) of the subjects in both shoulders. Sinnott et al.¹⁹ found a limited ROM in both shoulders in 43% of the persons with long-term paraplegia. One could imagine that a limitation of ROM of both shoulders even places a greater burden on the patient with respect to his/her possibilities to actively taking part in the rehabilitation program and achieve functional independence.

The mean residual ROM for each movement does not show much variation over time (Table 4.1). The range however is broad and shows that the severity of shoulder ROM limitations varies strongly between individuals. The clinical relevance of ROM is that unlimited ROM is conditional to be able to perform functional activities like transfers and reaching. Magermans et al.¹ described the requirements for upper extremity motion during activities of daily living in able-bodied persons. Their study showed that for, for example, reaching a mean glenohumeral elevation of 121.4 degrees is needed. This indicates that a substantial part of our subjects have such severe shoulder ROM limitations that they are restricted in this activity.

Course of limitations of shoulder ROM over time

Shoulder external rotation showed to be most at risk during inpatient rehabilitation and shoulder flexion after inpatient rehabilitation. Special attention is necessary in the acute phase and during inpatient rehabilitation to prevent limited shoulder external rotation. In the acute phase optimal shoulder positioning and early mobilisation are therefore still important since, in our study and the study of Waring et al.,²⁰ prolonged immobilisation is found to contribute to limited shoulder ROM. Start of active rehabilitation means a higher demand on the shoulder, which is thought to be a risk for overuse. In the literature a relationship has been described in subjects with paraplegia between specific joint forces and moments and measures of shoulder pathology.^{21, 22} The study of Van Drongelen²³ underlines the theory that muscle imbalance is a major risk factor for developing shoulder problems in SCI, such as pain and limitations in ROM.

After rehabilitation the focus of attention should shift towards prevention of shoulder flexion ROM limitations. Overuse of the shoulder could lead to damage of the structures of the shoulder and therefore lead to limited shoulder ROM.²⁴

Relationship between shoulder ROM limitations and personal and lesion characteristics, TSI1, spasticity of elbow flexors and extensors and pain

Having a tetraplegia showed to be the most important risk factor for shoulder ROM limitations during and one year after rehabilitation. At and above the level of C5, shoulder muscles are impaired, creating a disbalance of shoulder-musculature and making the shoulder therefore vulnerable to overuse. In the literature this imbalance is often postulated to be the cause for shoulder pain and ROM problems in wheelchair-dependent persons.^{10, 20, 21} Another important factor for shoulder functioning and functional end-level is the role of postural control.²⁵ This is often seen in the choice of wheelchair design (without trunk

stabilisation) and striving for independent transfers and manual wheelchairs, even in persons with tetraplegia. We critically should ask ourselves if those choices, on the long term could be justified.

Older age was found to be a risk factor for limited shoulder ROM. It has been shown that degenerative changes of the shoulder joint occur as early as 40 years of age and that aging with a SCI leads to an increase in physical assistance as most people, for example, need more help to make a transfer. Although shoulder ROM problems could be seen as a complication of SCI, age-related problems may contribute to shoulder problems and even may be amplified in SCI.^{4, 6, 7, 10, 13}

Prolonged immobilisation showed to be a risk factor for shoulder ROM limitations. The importance of early mobilisation and proper shoulder positioning has been described before.

Shoulder pain also showed to be strongly associated with limited shoulder ROM. In our study we clearly distinguished between musculoskeletal pain and other sensations of pain. Still one should be careful to address all reported pain to physical damage. The impact of pain is influenced not only by physical factors but also by psychosocial factors. It was beyond the scope of our study to investigate the aetiology and pathology of shoulder ROM. We, therefore, cannot answer the question what causes limitations of shoulder ROM. Studies that addressed radiographic changes of the shoulder in subject with SCI^{24, 26-28} show that physical changes in the shoulder of persons with SCI are often present but no consistent findings are found so far.

Spasticity of the elbow flexors increased the risk for developing limited shoulder flexion for the right shoulder only. In daily practice spasticity of the m. biceps is found to cause the most problems in shoulder ROM and is often treated (locally) medicamentous. Spasticity of the elbow extensors was found to be related to an increased risk for all measured shoulder ROMs for both shoulders. Spasticity of the m. triceps is, even when present, less often a reason for treatment. No literature was found to explain these results.

In contrast to the literature in our study female gender showed not to be a risk factor for limitation of shoulder ROM.

Limitations, clinical implications and future research

When interpreting the data of our study, one should bear in mind that we only measured wheelchair-dependent subjects, and therefore cannot generalize our results to those

persons with SCI who are not wheelchair dependent. In clinical practice wheelchair-dependent subjects seem to be mostly affected by shoulder problems, which justify this choice.

The drop-out at t4 could have caused bias. Using random coefficient analyses, however, gave us the possibility to include all present subjects at each measurement time and provided us realistic data on the occurrence of shoulder ROM limitations during each interval. Insight of the course of shoulder ROM problems was guaranteed by the longitudinal design of the study. This contributes to the understanding of this problem.

Limitations of shoulder ROM are common following SCI during and after inpatient rehabilitation. Especially people with tetraplegia are at risk of developing shoulder ROM limitations. Furthermore increased age, spasticity of elbow extensors, prolonged immobilisation and shoulder pain are determinants of an increased risk for shoulder ROM problems and require extra attention during rehabilitation and after discharge.

Future research ideally would involve a more comprehensive approach. A longitudinal study which addresses shoulder ROM and relates it to pain, structural changes and aging will give us more insight in the cause and development of shoulder ROM limitations. We should hereby keep in mind that not only physical changes can cause shoulder problems in people with SCI. To understand the complex relationship between shoulder ROM, shoulder pain and spasticity one should take also physiological causes, such as presence of depression into account. To really understand the magnitude of shoulder problems in people with SCI, one should determine what shoulder ROM is needed in wheelchair-dependent persons and ideally such a study should also measure restrictions in activities and participation.

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Chapter 5

The relation of **shoulder range-of-motion limitations** at discharge to limitations in activities and participation one year later **in persons with spinal cord injury**

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Correlation of shoulder range of motion limitations at discharge with limitations in
activities and participation one year later in persons with spinal cord injury.
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ABSTRACT

Objective: To study the relation between limited shoulder Range Of Motion (ROM) in persons with spinal cord injury (SCI) at discharge on the performance of activities, wheeling performance, transfers and participation one year later.

Design: Multicenter prospective cohort study.

Subjects: 146 newly injured subjects with SCI.

Methods: At discharge shoulder ROM was measured. One year later, Functional Independence Measure (FIM), ability to transfer, Wheelchair Circuit and Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) were assessed. Corrections were made for possible confounding factors (age, gender, level and completeness of injury, time since injury and shoulder pain).

Results: All subjects with limited shoulder ROM at discharge had a lower FIM motor score and were less likely (total group 5 times, subjects with tetraplegia 10 times) to be able to perform an independent transfer 1 year later. In the total group, subjects with limited shoulder ROM needed more time to complete the Wheelchair Circuit. In both groups no significant association with the PASIPD were found.

Conclusion: Persons with SCI and limited shoulder ROM at discharge are more limited in their activities than those without limited shoulder ROM, one year later.

INTRODUCTION

Upper extremity function in persons with spinal cord injury (SCI) is important for daily activities (ADL) such as dressing, washing oneself and combing the hair.^{1,2} For wheelchair-dependent persons an optimal shoulder Range Of Motion (ROM) is especially important for transferring independently,³ performing activities such as toileting, going in/out of bed, driving a car, but also for participating in sports and other leisure activities.

Unfortunately, persons with SCI who use a wheelchair for their daily mobility are at risk of developing shoulder impairments, like pain⁴⁻⁶ or limited joint ROM,^{4,5,7} both during initial rehabilitation as well as in the chronic phase. Shoulder ROM limitations in persons with SCI have shown to be a problem in persons with SCI during initial clinical rehabilitation as well as after discharge.⁴ Persons with SCI are at risk of develop a limited shoulder ROM because of immobilisation and spasticity,⁷ which for example leads to a 'frozen shoulder'.

An important milestone during initial rehabilitation is discharge. Discharge is the transition to the day-to-day home situation, where all learned skills (abilities) are implemented in daily practice (performance). Based on the person's functioning during initial inpatient rehabilitation a prediction of a person's functioning in the day-to-day situation is made and based on this evaluation home care, assistive technology (AT) and interventions (for example physiotherapy) are organized. Detecting those persons at risk of performing poorly on activities and participation as early as possible is important to improve rehabilitation where possible, and subsequently organize care, AT and interventions and ensure optimal functioning of the person at home. Understanding the longitudinal relation between shoulder ROM limitations in persons with SCI and performance in activities and participation is therefore important. When this relation shows to be present, it would be useful to study the influence of preventive interventions on shoulder ROM limitations and the influence of such interventions on performance on activities and participation. Although several studies on the relation between shoulder pain and its consequences on activities limitations and participation restrictions are available, only a few focus on the consequences of shoulder ROM limitations. To our knowledge, only one published study has investigated the consequences of limitations in shoulder ROM on activity limitations and participation restrictions in persons with SCI.⁴

Ballinger et al. showed that men with SCI (95% with paraplegia) and shoulder ROM problems had lower FIM scores, were less likely to push a wheelchair, and were more likely to need maximal assistance with transfers. They also reported poorer health.

To improve our understanding of the relevance of limitations in shoulder ROM for rehabilitation treatment in persons with SCI, more insight is needed in the relation between of shoulder ROM limitations on activities and participation in a longitudinal perspective.

Objective

In addition to our previous work on the longitudinal development of limitations in shoulder ROM,⁷ this study investigates the predictive value of limitations in shoulder ROM in persons with SCI (paraplegia and tetraplegia, as well as in the subgroup of those with tetraplegia alone) at discharge from initial clinical rehabilitation on the performance of activities, wheelchair performance, making a transfer and participation one year after discharge. We hypothesize that in persons with a SCI; a limited shoulder ROM at discharge predicts poorer performance on activities and participation one year later.

METHODS

Study design

Subjects

The present study was part of the Dutch prospective cohort study 'Physical strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of persons with SCI'.

Subjects admitted to one of the 8 participating rehabilitation centers between May 2000 and September 2003 were included if they met the eligibility criteria: acute SCI, classified as A, B, C or D on the International Standards for Neurological Classification,⁸ between 18 and 65 years of age, using a wheelchair for daily mobility, sufficient comprehension of the Dutch language to understand the purpose of the study and not having a progressive or psychiatric condition that could interfere with constructive participation in the study.⁹

Procedures

Measurements were conducted following a standardized protocol by trained research assistants at discharge of inpatient rehabilitation and 1 year after discharge. All subjects gave their written informed consent prior to the study, which was approved by the Medical Ethics Committee of the Stichting Revalidatie Limburg and the Institute for Rehabilitation Research.

At discharge from initial rehabilitation shoulder ROM was measured in all subjects. One year after discharge activities were assessed by total FIM motor score and wheelchair performance by measuring 2 items of the Wheelchair circuit. Also participation was determined one year after discharge by assessing the PASIPD. Possible confounders (age, gender, level of SCI, completeness of SCI, time since injury and presence of shoulder pain) were assessed at discharge to be able to correct for these factors.

Instruments/measurements

Personal and SCI characteristics

Age and gender of all subjects were recorded. Level and completeness of SCI were recorded according to the International Standards for Neurological Classification of SCI.¹⁰ Tetraplegia was defined as a neurological level of SCI above the T1 segment. A SCI was defined as motor complete when subjects met the criteria of the International Standards for Neurological Classification of SCI A or B.

Time since injury

For all subjects, time since injury (TSI) was determined as the time between the occurrence of SCI and the measurement time (noted in months).

Shoulder ROM

Following a standardized protocol, passive ROM of both shoulders was measured in sitting position for flexion, external rotation and abduction, using goniometry.¹⁰ Normal ROM was defined as: 180° for shoulder flexion, 60° for external rotation and 90° for glenohumeral abduction. A decrease of ROM of 10° or more was considered to be an impaired ROM. This cut-off point was chosen by experts working in the field of SCI. A limitation in shoulder ROM was therefore defined as a limitation of 10° or more in flexion, and/or external rotation and/or abduction in at least one shoulder.

Musculoskeletal pain of the shoulder

Subjects were asked in a standardized questionnaire if they experienced pain in the shoulder joint or in the muscles around the shoulder since the last measurement time (which was 3 months after starting active rehabilitation). Both shoulders were evaluated separately and musculoskeletal pain was scored as 0 when no pain was present or as 1 when pain was present in one or two shoulders.¹¹

Motor score Functional Independence Measure (FIM)

The FIM-Motor score consists of 13 items in 4 domains (self-care, continence, transfers and mobility). Each item can be scored from 1–7, 1 meaning fully dependent score and 7 meaning fully independent. Total score therefore can vary from 13–91.^{12, 13}

The Wheelchair Circuit

The total time of two time-dependent skills of the Wheelchair Circuit were chosen as outcome for our study.^{14–16} Time needed to perform a figure-of-8 shape and 15 m sprint were summed as outcome. Subjects with physical complications like major shoulder pain or presence of pressure sores were excluded from the test.

Transferring oneself

In our study we have used the item on transferring of the FIM motor score to define our outcome. Based on expert opinion we dichotomized the outcome to 'transfer independently', respectively FIM scores 5–7, into 1 or 0 for 'transfer with assistance' (FIM scores 1–4).¹²

Physical Activity Scale for Individuals with Physical Disabilities (PASIPD)

The Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) was used to quantify the physical activity levels of our participants. The PASIPD is a self-report instrument covering (a) leisure activities, such as walking and wheeling outside the home, light, moderate, and vigorous sport and recreation activities, and exercise to increase strength and endurance; (b) household activities, including light and heavy housework, home repair, lawn work, and outdoor gardening; and (c) occupational activity.¹⁷ Two of these questions, lawn work or yard care, and outdoor gardening, were merged into a single question, because this represents the Dutch situation more adequately. The PASIPD total score is expressed in a metabolic equivalent is defined as the amount of oxygen required per minute under quiet resting conditions. The maximum score of this adapted version is 182.3 metabolic equivalents.^{16, 18}

Statistical analyses

Shoulder ROM at discharge of rehabilitation was used as the independent variable in predictive models of the dependent variables of activities and participation 1 year after clinical rehabilitation. Total score of the Motor FIM, total time needed for the 2 wheelchair circuit items, ability to make an independent transfer and the total score of the PASIPD were selected as dependent variables (outcomes) for activities and participation. Possible

confounders that were taken into account were SCI characteristics (level, completeness, time since injury), age, gender and shoulder pain and selected on basis of previous literature and research.^{4, 5, 7} If the limitation was $>10^\circ$ ROM was scored as limited (1) and if the limitation was $<10^\circ$ ROM was scored as normal (0). The prevalence of impaired shoulder ROM was calculated for the total group and also separately for subjects with tetraplegia at discharge because shoulder ROM is more prevalent in this group. Differences between subjects with limited shoulder ROM and without limited shoulder ROM regarding gender, age, level and completeness of injury, TSI, presence of shoulder pain and limitations of shoulder ROM were tested with the student t-test or the Chi-square test.

Second, to investigate the effect of limitations in shoulder ROM on activities and participation at 1 year follow-up, the multilevel modelling programme MLwiN (MLwiN version 1.1; Centre for Multilevel Modelling, Institute of Education, London, UK) was used to correct for possible differences between study centers.^{19, 20} In a first step, limitations in shoulder ROM (no limitation = 0 and limitation = 1) was introduced in the basic model as independent variable. In a second step, personal characteristics (age, gender (men = 0; women = 1)), SCI characteristics (tetraplegia = 0; paraplegia = 1, incomplete = 0; complete = 1), TSI (months) and presence of shoulder pain (no = 0; yes = 1) were added to the basic model as possible confounding factors to define the final model. A factor added to the model was considered a confounder if adding that factor changed the beta of the model more than 10%. The regression coefficient for transferring oneself was converted to OR. An OR of 1 indicated that there was no association with this particular variable, an OR <1 indicated an increased risk of not being able to transfer without assistance in the presence of a limited shoulder ROM whereas an OR >1 indicated a decreased risk of being able to transfer without assistance in the presence of a limited shoulder ROM. Overall levels of significance was $p < 0.05$. This analysis was performed for the total group (N=146) and persons with tetraplegia (N=52).

RESULTS

Participant characteristics

The study population consisted of 146 subjects of whom 70% were male and 64% had paraplegia (Table 5.1). Forty-eight percent of the subjects were classified as AIS A, 16% AIS B, 19% AIS C and 14% AIS D. Thirty percent of the subjects (N=44) had limited shoulder ROM. The majority (N=42, 29%) of the subjects had limited shoulder flexion, 26 subjects (18%) had limited shoulder external rotation and 6 subjects (4%) had limited shoulder

Table 5.1 Patient characteristics: total group and subjects with tetraplegia (TP) including the p-value (Using student t-test or Chi-square test) of the differences between groups. Level of significance: $p < 0.05$.

	Total group (n=146)						Subjects with tetraplegia (n=52)					
	Persons with ROM limitation (n=44)			Persons without ROM limitation (N=102)			Persons with ROM limitation (n=32)			Persons without ROM limitation (N=20)		
	N	Mean (SD)/percentage	N	Mean (SD)/percentage	p-value	N	Mean (SD)/percentage	N	Mean (SD)/percentage	N	Mean (SD)/percentage	p-value
Possible determinants at discharge												
Male gender	31	70%	72	72%	0.913	21	68%	16	76%			0.852
Age (yrs)		43 (12)		39 (15)	0.173		41 (11)		38 (12)			0.531
Motor complete injury	26	60%	68	69%	0.650	15	48%	14	67%			0.562
TP	31	70%	21	20%	0.001*		-	-	-			-
TSCI (days)		411 (188)		279 (136)	0.005*		435 (204)		410 (202)			0.743
Shoulder pain	26	79%	31	30%*	0.002*	18	58%	7	33%			0.443
Outcomes 1 year after discharge												
Total score Motor FIM (range: 13–91)		48 (23)		70 (17)	<0.001*		44 (24)		59 (24)			0.0054
Time Wheelchair circuit (sec)		34 (18)		18 (8)	<0.001*		39 (17)		23 (11)			0.001*
Total score PASIPD (max score: 182.3)		12 (16)		21 (19)	0.021*		10 (15)		19 (26)			0.265
Ability to do transfer without assistance	18	41%	84	84%	<0.001	10	32%	14	67%			0.077

abduction. The results of the FIM Motor score and ability to make a transfer were missing in 2 subjects. Total score of the PASIPD was missing in 13 subjects and performance time of the Wheelchair Circuit was missing in 33 subjects.

The t-test and Chi-square test showed that subjects with limited shoulder ROM at discharge had more often a tetraplegia, a longer duration of the injury and suffered more shoulder pain than those without limited shoulder ROM. Furthermore they were less often able to transfer without help at 1 year after discharge, scored longer time on the Wheelchair Circuit items and had a lower PASIPD score.

In the group of subjects with tetraplegia only, also significant differences between those with shoulder ROM limitations and without shoulder ROM limitations were found. Those with a limited shoulder ROM at discharge from initial rehabilitation had more shoulder pain at discharge. 1 year after discharge they were less often able to transfer without help, needed a longer time on the Wheelchair Circuit and had a lower PASIPD score.

Association of shoulder ROM limitation at discharge with activities and participation 1-year later

Tables 5.2a (total group) and 5.2b (persons with tetraplegia only) show the relation between limited shoulder ROM at discharge and the FIM motor score, Wheelchair circuit, PASIPD and transferring one year later. Both tables show both the basic models and the models after including confounding factors in the regression models. Significant relationships between ROM limitations and activities and participation were found in the basic models. In the total group and after correction for confounders, subjects with limited shoulder ROM had lower FIM motor scores, needed more time to complete elements of the Wheelchair Circuit, and were 5 times less likely to be able to perform an independent transfer. The relation between limited shoulder ROM and the PASIPD was significant in the basic model, but was not significant taking into account the confounders.

For the subjects with tetraplegia, subjects with limited shoulder ROM had a significantly lower FIM motor score and were 10 times less likely than subjects without limited shoulder ROM to be able to perform an independent transfer. No significant associations between shoulder ROM limitation and time needed for the Wheelchair Circuit and the PASIPD score were found in subjects with tetraplegia.

Table 5.2a Relation of limitation of limited shoulder ROM at discharge with FIM motor score, wheelchair performance, PASIPD and transferring oneself one year later in the total study population (N=146). Level of significance: p<0.05.

	Activity					Participation				
	FIM motor score (13–91)					Transferring oneself				
	Beta (SE)	95% CI	p-value	Beta (SE)	95% CI	p-value	Beta (SE)	OR	p-value	95% CI
Basic model										
Constant	70.14 (1.89)			18.35 (1.28)			1.66 (0.27)			21.21 (1.92)
Limited ROM	-22.49 (3.44)	-25.93–-12.45	<0.001	16.34 (2.34)	11.48–20.93	<0.001	-1.99 (0.41)	0.1	<0.001	-12.74–5.22
Model with confounders included										
Constant	78.99 (4.53)			14.9 (2.50)			4.01 (0.95)			26.00 (5.29)
Limited ROM	-10.85 (3.39)	-17.49–-4.12	<0.001	10.10 (2.51)	5.18–15.02	<0.001	-1.67 (0.57)	0.2	<0.001	-5.24 (4.03)
Age	-	-	-	-	-	-	-	-	-	-
Gender	-	-	-	-	-	-	-	-	-	-
Completeness	-	-	-	-	-	-	-1.98 (0.69)	0.1	<0.001	-
Lesion level	8.28 (3.37)	1.63–14.83	0.01	-5.42 (2.45)	-10.22–-0.62	0.03	1.24 (0.58)	3.5	0.03	-
TSI	-1.65 (0.27)	-2.18–-1.12	<0.001	0.85 (0.21)	0.43–1.26	<0.001	-0.14 (0.05)	1.5	0.01	-0.64 (0.33)
Shoulder pain	-	-	-	-	-	-	-0.16 (0.53)	0.9	<0.001	-

ROM = range of motion; SCL = spinal cord injury; FIM = Functional independence measure; PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; TSI = time since injury; SE = standard error; 95% CI = 95% confidence interval; OR = odds ratio.

Table 5.2b Relation of limited shoulder ROM at discharge with FIM motor score, wheelchair performance time, PASIPD and transferring oneself at one year later in the subjects with tetraplegia (N=52). Level of significance: p<0.05.

	Activity						Participation			
	FIM motor score (13–91)			WC performance time			Transferring oneself			PASIPD (182.3)
	Beta (SE)	95% CI	p-value	Beta (SE)	95% CI	p-value	Beta (SE)	95% CI	p-value	
Basic model										
Constant	56.38 (5.44)			16.43 (4.27)			0.69 (0.46)			
Limited ROM	-14.28 (7.05)	-28.08--0.48	0.04	9.93 (5.53)	-0.91--20.77	0.07	-1.43 (0.60)	-6.51 (5.28)	0.02	15.9 (4.08)
										0.22
Model with confounders included										
Constant	73.65 (13.99)			21.90 (8.91)			4.59 (1.99)			31.20 (11.69)
Limited ROM	-15.96 (6.36)	-28.43--3.49	0.01	8.77 (5.57)	-2.51--19.69	0.11	-0.97 (0.90)	-5.53 (5.41)	0.03	-16.31--5.07
Age	0.56 (0.29)	0.00--1.13	0.05	-			-			-
Gender	-			-			-			-
Completeness	-21.74 (6.40)	-34.28--9.20	0.00	-			-2.35 (0.84)	-9.84 (5.13)	0.01	-19.90--0.22
TSI	-1.17 (0.48)	-2.11--0.23	0.01	-			-	-0.11 (0.06)	0.01	-0.23--0.01
Shoulder pain	-			10.69 (5.39)	0.13--21.25	0.05	-			-

ROM = range of motion; SCI = spinal cord injury; FIM = Functional independence measure; PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; TSI = time since injury; SE = standard error; 95% CI = 95% confidence interval; OR = odds ratio.

DISCUSSION

This study showed that persons with a SCI and limited shoulder ROM at discharge performed worse on activities one year later as measured with the FIM motor score, the ability to make a transfer independently and the time needed to complete the Wheelchair Circuit. This relation was not found in subjects with a tetraplegia. No significant relation was found in persons with a SCI and limited shoulder ROM and participation, measured with the PASIPD.

Our results confirm the findings of Ballinger et al.,⁴ who showed that subjects with chronic SCI and a limitation in shoulder ROM were more likely to need maximal assistance for transfers and reported a lower FIM score. Our study, however not only analysed the total group, but analysed those with tetraplegia separately, and included Wheelchair Circuit items as an outcome on activity and the PASIPD as outcome on participation. The study of Salisbury et al. on shoulder pain, range of motion, and functional motor skills after acute tetraplegia in 41 subjects measured during inpatient rehabilitation first within one week after admission and second at discharge⁵ was found to be inconclusive. Their outcomes were not clearly defined and statistical analyses of the relation between the effect of shoulder ROM and these outcomes of functioning were not described in their study. In our study we defined the outcomes clearly and focus on the highly important period between discharge and the first year after discharge. As stated before, this period is characterized by utilizing skills learned in inpatient rehabilitation for activities and participation in everyday life in the home environment.

No relations between limitations in shoulder ROM and PASIPD total scores were found. A possible reason for this finding is that the PASIPD score is more strongly influenced by other factors, for example, having an adapted car or the person's motivation to be physically active. In both the total group and the subjects with tetraplegia we found a significant difference in time needed for the Wheelchair Circuit between those with and without a limited shoulder ROM. However, after controlling for confounding factors we found only in the total group a significant relation between a limited shoulder ROM and time needed for the Wheelchair Circuit items. One explanation for this outcome might be the smaller sample size of the subgroup of subjects with a tetraplegia. Another explanation might be that other confounding factors, for example level of the SCI for which we did not control in this subgroup could have a significant relevance in this group. In our study population a higher level of injury was associated with longer time needed to complete the items of the Wheelchair Circuit, but sample size for each individual level of injury was too small to perform analyses.

We have shown in the current study that in persons with SCI (persons with paraplegia and tetraplegia) limited shoulder ROM at discharge is related to limitations in their daily activities as measured with the FIM, in transferring and for the total group in the performance time on a figure-of-8 shape and the 15 m sprint. Discharge is a milestone during rehabilitation; it is the transition to the home situation, where all learned skills (abilities) are to be implemented in daily practice (performance), based on the person's functioning during initial inpatient rehabilitation a prediction of a person's functioning in the day-to-day situation is made. Based on this evaluation, home care, assistive technology (AT) and interventions (for example physiotherapy) are organized. Our study showed that persons with limited shoulder ROM at discharge perform worse on activities and it is possible to detect at discharge from initial rehabilitation those persons at risk. This finding is relevant for rehabilitation such as the organisation of care, AT and interventions and future research.

Limitations and future studies

One of the inclusion criteria for the study was that subjects had to be (mainly) wheelchair dependent. Although one can assume that shoulder ROM limitations affect wheelchair-dependent persons most, it limits the external validity of the study to those subjects that are mainly walking for their mobility.

Although we included 146 persons with SCI in our study, the number of participants is limited, especially for the analysis in the group with tetraplegia. For this study we could use only the data of those subjects measured at discharge as well as one year later. Due to several reasons 23 subjects were lost to follow up. Especially the wheelchair performance items had missing data. Subjects with complications, such as major shoulder pain or pressure sores were excluded for this item. Although this is inevitable in a study in subjects with SCI it lowers the number of subjects in the analysis. This makes it particularly difficult to substantiate an association between shoulder ROM, activities and participation in persons with tetraplegia, because of the limited number of confounders that can be put into the multilevel regression model. We therefore might have not included all possible confounders in this study.

Our study did show a relation between limited shoulder ROM at discharge and performing worse on activities one year later but could not show a causal relationship. Future studies should focus on the influence of methods preventing shoulder ROM limitations to reflect causality.

CONCLUSION

This study shows that persons with a spinal cord injury with a limited shoulder ROM at discharge from initial clinical rehabilitation are more limited in their activities one year after discharge.

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Chapter 6

Association of **shoulder problems** in persons with spinal cord injury at discharge from inpatient rehabilitation with activities and participation at 5 years later

Eriks-Hoogland IE, de Groot S, Snoek G, Stucki G, Post MW, van der Woude LHV.
Shoulder pain and shoulder range of motion limitations in persons with SCI at discharge from inpatient
rehabilitation and correlations with limitations in activities and participation at 5 years after discharge.
(Submitted)

ABSTRACT

Objective: To examine the association of musculoskeletal shoulder pain and limitations in shoulder range of motion (ROM) at discharge from first rehabilitation with activities and participation five years later in persons with spinal cord injury (SCI).

Design: Prospective cohort study.

Participants: 138 subjects with a newly acquired SCI.

Setting: Eight SCI specialized rehabilitation centers.

Interventions: Not applicable.

Main outcome measures: Peak exercise performance (POpeak), Wheelchair skills test (WST), Functional Independence Measure (FIM)-Motor Score, ability to transfer, Physical activity Scale for subjects with a Disability (PASIPD), Mobility Range and Social Behavior scales of the Sickness Impact Profile 68 (SIPSOC) and employment status.

Results: Mean age of the subjects at discharge was 39 years, 72% were male, 32% suffered a tetraplegia, and in 65% the SCI was motor complete. At discharge 39% reported shoulder pain and 32% had a limited shoulder ROM. In the analyses of variance Shoulder ROM limitation, but not shoulder pain was associated with all but one outcomes at 5 years. In the regression analyses ROM limitations of the shoulder were negatively associated with ability to transfer (Beta -0.26, $p=0.001$), FIM-Motor Scores (Beta -13.45, $p<0.001$), and return to work (Beta -3.3, $p=0.001$) 5 years after discharge. No significant associations were found with POpeak, performance of time of WST, SIPSOC, and the PASIPD.

Conclusion: The presence of limitations in shoulder ROM, but not shoulder pain, at discharge is associated with limitations in activities and employment status 5 years later.

INTRODUCTION

Persons with a spinal cord injury (SCI) are more at risk for developing overuse related shoulder problems than those without SCI.¹ Estimations of limitations in shoulder ROM vary between 29% and 70%,^{2,3} while shoulder pain is reported in up to 67% in persons with SCI.⁴⁻²⁰

Persons with limited shoulder ROM at discharge show a lower Functional Independence Measure (FIM)-Motor Score and are less likely to be able to perform an independent transfer one year later and need more time to complete the wheelchair circuit.²¹ Of those persons with shoulder pain, 86% reports limitations in daily activities and restrictions in participation because of shoulder pain.^{5, 22, 23} Furthermore, 84% of the persons with shoulder pain report restrictions in sports and leisure^{5, 24} and, finally, shoulder pain was shown to be associated with lower perceived health,²⁵ lower quality of life^{18, 24, 26} and an increased use of assistive devices.⁹

Therefore it is necessary to know the association between shoulder problems during inpatient rehabilitation and long term activities and participation in order to timely intervene. The current study is a follow-up study of our earlier studies on shoulder pain and on the association between shoulder ROM and activities and participation 1 year after discharge from inpatient rehabilitation.²¹

The objective of the current study was: To use the bio-psychosocial framework of International Classification of Functioning, Disability and Health (ICF)²⁷ to examine the associations of musculoskeletal shoulder pain and limitations in shoulder ROM at discharge from first rehabilitation with activity limitations and participation restrictions 5 years after discharge (Figure 6.1).

METHODS

Study design

A multicenter prospective cohort study was conducted with measurements at discharge from inpatient rehabilitation and five years after inpatient rehabilitation.

Subjects

Subjects were persons with a recently acquired SCI who were included in the longitudinal Dutch cohort study 'Physical strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of individuals with spinal cord injury'.²⁸ Inclusion criteria were; (1) age

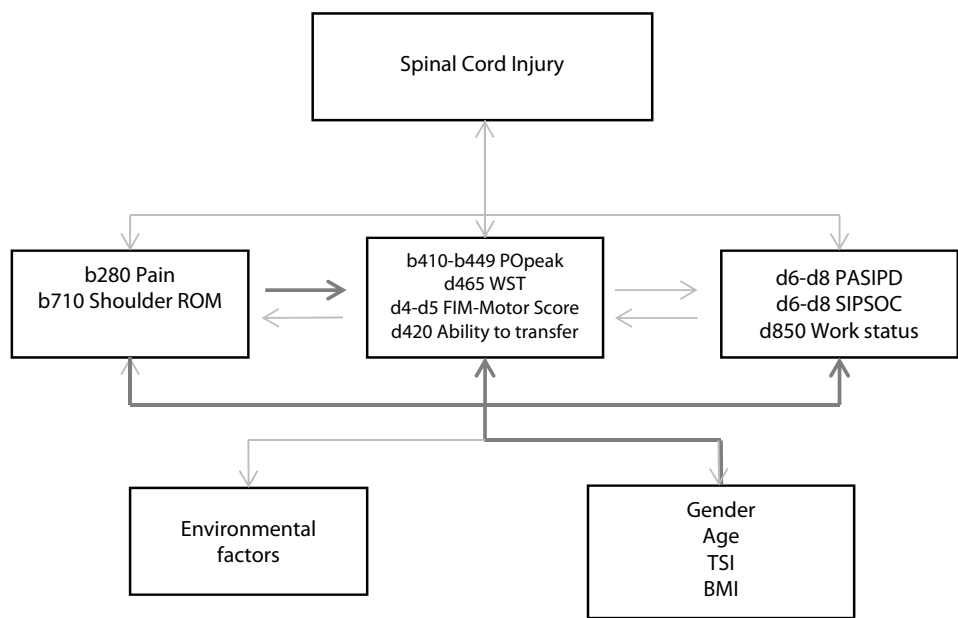


Figure 6.1 Relationship of shoulder pain and shoulder ROM limitations within the scope of this study, described with the framework of the International Classification of Functioning, Disability and Health (ICF).

between 18 and 65 years; (2) AIS grade A, B, C, or D; (3) expected permanent wheelchair dependency for long distances.

For the current study subjects (N=138) who completed the measures of shoulder ROM and pain assessment at discharge and completed at least the questionnaire data 5 years after discharge were included.

The research protocol was approved by the Medical Ethics Committees of the SRL/iRv and University Medical Center Utrecht. All subjects gave written informed consent.

Instruments

All clinical measurements were assessed by trained physicians and research assistants.

Shoulder pain

Subjects were first asked whether they experienced any pain in their joints or muscles. If so, patients were asked to rate the severity of shoulder pain for both shoulders separately

on a scale of 0–5 (0 = no pain, 1 = very mild, 2 = mild, 3 = moderate, 4 = severe, and 5 = very severe).¹⁴ A patient was considered to have shoulder pain if he/she suffered pain in at least one shoulder (no pain = 0, pain = 1). In cases where both shoulders were affected, the shoulder with the highest pain score was included in the analysis.

The questionnaire tried to distinguish musculoskeletal pain from neuropathic pain as best as possible by also asking the character of the pain.³¹

Shoulder range of motion

Passive ROM of both shoulders was measured in the sitting position²⁹ for forward flexion, external rotation and abduction using goniometry.³⁰ Normal ROM was defined as: 180° for shoulder forward flexion, 60° for external rotation and 90° for glenohumeral abduction. A decrease in ROM of 10° or more in one of the movements in one or both shoulders was considered to be an impaired ROM (0 = no impaired ROM, 1 = impaired ROM). This cut-off point was chosen by experts working in the field of SCI and used in our earlier publications.³

²¹ In cases where both shoulders were affected, the shoulder with the most limited ROM score was included in the analysis.

Functional Independence Measure (FIM)-Motor Score

The FIM-Motor Score consists of 13 items in 4 domains (self-care, continence, transfers and mobility). Each item can be scored from 1 to 7, where 1 = fully dependent and 7 = fully independent. The total score can therefore vary from 13 to 91.³²

Wheelchair Skills Test (WST)

Of the wheelchair circuit the total time needed to perform a figure-of-8 shape and a 15 m sprint was chosen as outcome for this study.^{33, 34} Subjects with physical complications such as major shoulder pain or presence of pressure sores were excluded from the test.

Transferring oneself

We used the FIM-Motor Score item on transfers to define this outcome. Based on expert opinion we dichotomized the outcome into 1 or 0, for 'transfer independently' (FIM-Motor Scores 5–7) and 'transfer with assistance' (FIM-Motor Scores 1–4), respectively.³²

Peak exercise performance (POpeak)

POpeak was measured with a graded maximal wheelchair exercise test on a motor-driven treadmill.^{35, 36} POpeak was defined as the power output at the highest inclination that the

participant could maintain for at least 30 seconds. Subjects with physical complications such as major shoulder pain or presence of pressure sores were excluded from the test.

Physical Activity Scale for Individuals with Physical Disabilities (PASIPD)

The PASIPD was used to quantify the physical activity levels of our subjects. The PASIPD is a self-report instrument³⁵ covering: (i) leisure activities, (ii) household activities, and (iii) occupational activities. Two of these questions, lawn work or yard care, and outdoor gardening, were merged into a single question, because this represents the Dutch situation more adequately. The PASIPD total score is expressed in a metabolic equivalent, which is defined as the amount of oxygen required per minute under quiet resting conditions. The maximum score of this adapted PASIPD is 182.3 metabolic equivalents.³⁶

Employment status

Work status 5 years after discharge was defined as having paid work for 1 hour a week or more, following earlier publications from this cohort.³⁷ Subjects of retirement age (65 or older) at follow-up were excluded from this analysis.

Mobility Range and Social Behavior scales of the Sickness Impact Profile 68 (SIPSOC)

Participation was also measured with two subscales from the 68-Item Sickness Impact Profile (SIP68). The SIP68 is a questionnaire that measures health-related functional status by assessing the impact of disease or disability on behavioral limitations.^{38, 39} and its measurement concept compares closely with the ICF.²⁷ The sum score (0–22) of two subscales (Mobility Range and Social Behavior or so called SIPSOC) indicate participation restrictions.

Personal and lesion characteristics

Possible confounders of the relationship between shoulder problems and activity limitations and participation restrictions that were included in the analyses were age and gender (men = 0; women = 1), time since injury and level and completeness of SCI and being overweight. All parameters were measured at discharge from inpatient rehabilitation.

Level and completeness of SCI were recorded according to the International Standards for Neurological Classification of SCI (tetraplegia (above T1 segment) = 0; paraplegia = 1, incomplete = 0; complete = 1).⁴⁰

Overweight was defined using the cut-offs for SCI suggested by Laughton et al. (no overweight or BMI <22 = 0, overweight or BMI ≤22 = 1).⁴¹ Mass was either measured using

a wheelchair scale or a weighting lift scale. Body height in meters was retrieved by the subject's self-report.

Statistical analysis

Descriptive data were calculated with SPSS 18.0 on demographic and lesions characteristics at discharge from first inpatient rehabilitation as well as on POpeak, FIM-Motor Score, WST and ability to make an independent transfer at discharge using independent Student t-tests and Chi-square tests ($p < 0.05$). Included in the analyses were those persons that completed the measurements at discharge and at least the SIPSOC and PASIPD questionnaires 5 years after discharge.

First, analysis of variance (ANOVA) was performed to describe the association of the independent variables (shoulder pain and shoulder ROM) with the outcome variables. In the analyses we distinguished 4 subgroups; a) no ROM limitations/no pain, b) ROM limitations/no pain, c) no ROM limitations/pain and d) ROM limitations/pain ($p < 0.05$).

Secondly, using backward regression analyses, shoulder pain and shoulder ROM limitations at discharge were entered as independent variables to predict activities and participation five years later. Shoulder ROM and shoulder pain were included in all analyses, whereas possible confounders that were taken into account, were age, gender, SCI characteristics (level and completeness), time since injury and being overweight. Insignificant confounders at an alpha level of 0.1 were eliminated using a stepwise backward procedure. In a first step, personal characteristics, SCI characteristics, TSI (months) and presence of overweight were added to the basic model as possible confounding factors. In a second step, limitations in shoulder ROM and presence of shoulder pain was introduced in the basic model as independent variable to define the final model ($p < 0.05$).

RESULTS

Descriptive analyses

198 subjects participated in the discharge measurement. Of these 138 subjects completed the discharge measurements for ROM and shoulder pain as well as the SIPSOC and PASIPD 5 years later.

The descriptive characteristics of the subjects analysed in this study (called 'Participants') and subjects that not fulfilled the above mentioned inclusion criteria (called 'Lost to follow-up') are displayed in Table 6.1. Significant differences between groups were only found for completeness of SCI, showing a lower percentage of motor incomplete SCI in the lost to follow-up group, and limitation of shoulder ROM, showing a higher percentage of shoulder ROM limitations in the lost to follow-up group.

Association of shoulder ROM limitations and shoulder pain at discharge with activities and participation five years later

Table 6.2 shows the results analyses of variance (ANOVA). The differences in outcomes at 5 years show to be mainly by a limitation in shoulder ROM and not by shoulder pain.

Table 6.1 Descriptive characteristics at discharge from inpatient rehabilitation of subjects in the study group (participants) and persons that were lost to follow up. Described are numbers and where applicable the mean and range of the outcome measures. $P \leq 0.05$. Significant differences marked with an *.

Characteristics at discharge (N=198)	Participants (N=138)		Lost to follow-up (N=60)	
	N	%	N	%
Male	99	71.7	46	76.6
Type of injury				
Tetraplegia	47	34.1	18	30.0
Motor Complete (AIS A or B)	90	65.2	31	51.6*
Presence of any shoulder pain	54	39.1	24	40.0
Presence of limitation in shoulder ROM >10°	44	31.9	21	35.0*
BMI >22 kg/m ² (N=137)	84	61.3	33	55.0
Ability to make independent transfer	90	65.0	38	63.3
	Mean	Range	Mean	Range
TSI (days) (mean, range)	311	98–809	337	79–818
Age (y) (mean, range)	39.4	18.6–66.3	44.5	19.3–66.2
BMI (kg/m ²) (mean, range) ²	23.5	15.3–39.3	23.7	15.5–39.3
Severity of shoulder pain right ³	2.53	1–5	2.73	1–5
Severity of shoulder pain left ³	2.63	1–5	2.93	1–5
POpeak (watt)	45.5	4.6–117.5	40.1	5.9–63
WST (sec.)	22.7	11.0–79.0	22.8	11.0–63.0
FIM-Motor Score	98.4	41–125	97.5	48–124

¹ Analyses of the excluded group are done only on data of those persons that were alive 5 years after discharge.

² Assessment of BMI at discharge was missing in 5 cases in the excluded group and in 1 case in the study group.

³ Mean shoulder pain severity score given for those subjects with shoulder pain only.

* Significant difference between Study group and excluded group.

Table 6.2 Results of the analyses of variance of the association of shoulder ROM limitation and shoulder pain at discharge from inpatient rehabilitation with POpeak, WST performance time, Ability to transfer and FIM-Motor Score, PASIPD, SIPSOC and work status 5 years after discharge from inpatient rehabilitation. Statistical significant difference was defined $p \geq 0.05$.

	Activities							
	POpeak (watt)		WST performance time (sec.)		FIM-Motor-Score		Ability to transfer independent	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N/total N	% of N
Total sample	70	54.7 (28.0)	77	21.4 (22.8)	138	62 (23)	88/138	63.8
Subsamples								
No ROM limitations/no pain	40	64.3 (26.6)	42	16.2 (6.6)	68	69.8 (19.2)	59/61	96.7
ROM limitations/no pain	5	43.9 (33.4)	7	26.3 (14.7)	14	52.1 (23.4)	7/7	100
No ROM limitations/pain	17	44.0 (22.6)	18	27.5 (40.4)	28	68.6 (17.9)	22/26	84.6
ROM limitations/pain	8	39.2 (26.0)	10	29.0 (23.6)	28	42.6 (24.0)	11/27	40.7
	p		p		p		p	
ANOVA								
Main effect pain	0.270		0.240		0.453		0.674	
Main effect ROM	0.048		0.371		<0.001		<0.001	
Interaction	0.246		0.488		0.265		0.883	
	Participation							
	PASIPD (METS)		SIPSOC		Work >1 hour per week			
	n	Mean (SD)	N	Mean (SD)	N/total N		N (%)	
Total sample	133	19.9 (19.6)	136	6.36 (4.37)	60/128		46.9	
Subsamples								
No ROM limitations/no pain	68	24.3 (21.8)	67	5.30 (4.26)	34/62		54.8	
ROM limitations/no pain	13	16.2 (16.6)	14	6.79 (4.53)	3/12		25.0	
No ROM limitations/pain	27	18.0 (15.2)	28	6.38 (4.56)	15/27		55.6	
ROM limitations/pain	25	14.0 (18.5)	27	8.50 (4.84)	8/27		29.6	
	p		p		p			
ANOVA								
Main effect pain	0.367		0.281		0.500			
Main effect ROM	0.090		0.012		0.002			
Interaction	0.587		0.512		0.878			

Backward logistic regression analyses

Table 6.3 displays the associations between the presence of shoulder ROM limitations and shoulder pain on outcomes at discharge 5 years later while correcting for possible confounding factors.

After adding the confounding factors to the model, shoulder ROM, but not shoulder pain, was associated with lower ability to make an independent transfer, lower FIM-Motor Score and lower likelihood to return to work. No significant associations were found between shoulder ROM nor shoulder pain at discharge with POpeak, performance time of WST, SIPSOC, and the PASIPD scores.

DISCUSSION

Corrected for possible confounders, shoulder ROM at discharge, but not shoulder pain, was associated with lower ability to make an independent transfer, lower FIM-Motor Score and lower likelihood to have employment for at least one hour per week five years after discharge. In a previous study of the Dutch Umbrella project on the same study population, the relation of shoulder ROM limitations at discharge with activities and participation one year later was studied and showed that subjects with limited shoulder ROM at discharge had a lower FIM-Motor Score and were less able to perform an independent transfer and needed more time to complete the WST items. The current study showed that the association with FIM-Motor Score and ability to transfer holds also after five years. No association with WST items was found anymore after 5 years, but limitations in shoulder ROM showed to be associated with lower work participation after 5 years. Our results partly confirm the results of former studies on the relation of shoulder pain and shoulder ROM limitations with activities and participation in persons with SCI. Ballinger et al.²⁵ studied the relationship of shoulder pain and shoulder ROM limitations in a cross-sectional sample of 89 adult men with traumatic SCI living in the community and showed that persons with shoulder ROM limitations had lower FIM-Motor Scores, were less likely to push their own wheelchair and were more likely to need maximum assistance with transfers. That study also showed that shoulder pain was unrelated to functional outcomes measures, but mean score on the Craig Handicap Assessment and Reporting technique (CHART) was negatively related to shoulder pain. Gutierrez et al.²⁴ performed a survey on shoulder pain amongst 80 wheelchair-dependent persons with chronic SCI (mean duration of SCI 20 years) and reported that shoulder pain was associated with reduced physical activity (lower PASIPD scores) but they

also found no relationship between shoulder pain and community activities. Hierarchical regression analysis was not performed and therefore it remains unknown if the relation would hold taking confounders into account. Finally, the relation of shoulder pain with limitations in activities and participation was studied by Salisbury et al. in a cross sectional study (survey) in 27 subjects with a tetraplegia 2–4 years post-injury.^{17,18} They showed that shoulder pain was related to specific activities (as measured with the Wheelchair User's Shoulder Pain Index) and showed that presence of shoulder pain was inversely associated with quality of life (QOL). Unfortunately, this study did not investigate the association of shoulder pain with performance of activities and participation. All above mentioned studies were cross sectional in relatively small study populations.

We were surprised that, in the regression analyses, shoulder pain at discharge was not associated with limitations in activities and restrictions in participation 5 years later. In another study on trajectories of shoulder pain in the same population, approximately 33% of the subjects suffered shoulder pain and subjects with shoulder pain at start of rehabilitation were shown to have shoulder pain throughout the rehabilitation, 1 year and 5 years after discharge (they follow a so-called 'High Pain' trajectory).⁴² A reason for this lack of association might be that shoulder pain influences activities and participation only in very severe cases. Our clinical experience is that subjects with shoulder pain present themselves in a late stage. This is also confirmed by a study on acromioclavicular (AC-) joint arthritis in subjects with SCI,⁴³ which showed that persons with SCI tend to present themselves with a more advanced stage of AC-joint arthritis compared to able-bodied subjects. Also, persons with severe shoulder pain were excluded from the maximal exercise test and WST, which might have resulted in a underrepresentation of persons with shoulder pain on our study population. This might have influenced the results of the study and reason for not finding significant associations between shoulder ROM nor shoulder pain at discharge with POpeak, performance of time of WST, SIPSOC, and the PASIPD was found. Another reason for this lack of association is that these scores are more strongly influenced by other factors; for example, having an adapted car or the person's motivation to be physically active.

Limitations

Subjects of the current study were persons with SCI between 18 and 65 years with expected permanent wheelchair dependency admitted to a rehabilitation center. This influences the representativeness of the population and thereby the degree to which the results of our study can be generalized to the whole population of persons with SCI e.g. those who are able to walk.

Furthermore, the assessment of pain in subjects with SCI is difficult. Especially in subjects with SCI C5 or higher it is difficult to distinguish between neuropathic pain and musculoskeletal pain. Shoulder pain typically presents with pain in dermatome C5. All subjects in our study with a sensory level of C5 or higher had preserved sensation above, at or below the neurological level. In the questionnaire we tried to distinguish neuropathic pain from musculoskeletal pain by asking for the character of pain.³¹ However, we cannot completely rule out that some subjects could not clearly distinguish between neuropathic pain and musculoskeletal pain.

Although we included the so far largest SCI cohort population to study shoulder pain, unfortunately some subjects were lost to follow-up or did not complete all measures in the study.²⁸ In Table 6.1 we have described the characteristics of study subjects and those who were not included in the analyses. No significant differences were found between the groups except for completeness of injury (in the excluded group more incomplete injuries) and presence of shoulder ROM limitations (in the excluded group more patients with limitations in shoulder ROM). Our study population shows an underrepresentation of the persons with shoulder ROM limitation and it can be assumed that our results show also an underrepresentation of the effect of shoulder ROM on activities and participation.

Finally, for the wheelchair capacity test and the WST, having major shoulder problems was one of the exclusion criteria to absolve this test. This might have influenced the selection of subjects introducing bias, causing an underrepresentation of persons with shoulder pain in the analyses.

Implications for clinical practice

Clinicians should be aware that persons with shoulder ROM limitations at discharge are at risk for limitations in activities and restrictions in work participation. Interventions to preserve full ROM of the shoulder joint should be a goal during and after inpatient rehabilitation. A timely planning of adaptations and interventions might prevent a suboptimal independence and integration of persons with a SCI in community living, especially in work.

Furthermore, a yearly evaluation of the patient as part of the rehabilitation aftercare model should include shoulder examination with assessment of ROM and if indicated, diagnostics with for example Magnetic Resonance Imaging (MRI) to 'catch' persons with shoulder problems in a phase where conservative treatment still can be successful.

Implications for research

Future research ideally would involve a more comprehensive approach. A longitudinal study, which addresses shoulder ROM and shoulder pain, but also structural changes, clinical testing, diagnostics and kinematic analyses of wheelchair propulsion and influence on activities and participation will give us more insight in the cause and development of shoulder ROM limitations and pain. Furthermore a uniform assessment of pain, for example as defined by 'The international spinal cord injury pain basic data set' warrants comparability of study results.³¹

CONCLUSION

The presence of limitations in shoulder ROM, but not shoulder pain at discharge, is associated with limitations in activities and employment 5 years later. These findings are relevant for the planning of the rehabilitation, in the organization and adaptation of the environmental factors for individual patients after discharge, and is a starting point for future research.

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Chapter 7

General discussion



The objective of the present thesis was to gain: 1) understanding in structural changes, prevalence and course of shoulder problems (pain and ROM) over time and, 2) to study the complex association between aspects of shoulder structure, shoulder function and activities and participation using the ICF as a framework. As such, this thesis intended to offer a step towards healthy ageing of persons with a SCI.

MAIN FINDINGS

Body structures; the AC joint

In the study on AC joint arthrosis (Chapter 2), performed at the Swiss Paraplegic Centre, the objective was to compare the prevalence, severity and risk of AC joint arthrosis in a SCI population presenting with shoulder pain compared to a non-SCI population presenting with shoulder pain.

We found that although prevalence of AC joint arthrosis in persons with SCI was equal to the prevalence in the able-bodied persons, persons with SCI presented with a more severe stage of AC joint arthrosis.

Body functions; shoulder pain

In the study on shoulder pain trajectories in persons with SCI (Chapter 3) we tried to distinguish different trajectories of shoulder pain in persons with SCI. We identified three distinct shoulder pain trajectories in patients with SCI that participated in the Dutch Umbrella and SPIQUE studies during first rehabilitation until five years after discharge (1) a 'No or Low pain' trajectory (64%), (2) a 'High pain' (30%) trajectory and (3) a trajectory with a 'Decrease of pain' (6%). At risk for belonging to the 'High pain' trajectory were persons with tetraplegia and those with a limited passive shoulder ROM at the start of active rehabilitation.

Body functions; shoulder ROM

In the cohort of the Umbrella study we evaluated the prevalence and course of passive shoulder range of motion in wheelchair-dependent persons with a new SCI, during first rehabilitation and 1 year after discharge (Chapter 4).

We found that a limited shoulder ROM is common in wheelchair-dependent persons. At the start of active rehabilitation the chance of having impaired shoulder external rotation or

abduction for the left shoulder is 2.2 times higher than at discharge ($p < 0.05$). Three months after the start of active rehabilitation, we found a 2.6 times higher chance of having impaired shoulder external rotation for the right shoulder compared with time at discharge. One year after discharge a significantly decreased chance of having impaired shoulder flexion was found compared with discharge.

Tetraplegia, increased age, spasticity of elbow extensors, longer duration between injury and start of active rehabilitation and shoulder pain were associated with an increased risk for shoulder ROM problems and require extra attention.

Activities and participation: the association with shoulder ROM and shoulder pain

In the participants of the Dutch Umbrella and SPIQUE studies, we analyzed the association between limited shoulder ROM in persons with SCI at discharge and the performance of activities, wheeling performance, transfers and participation one year (Chapter 5) and five years (Chapter 6) later.

We showed that, again in wheelchair-dependent participants with SCI of the Dutch Umbrella Study, those persons with a limited shoulder ROM at discharge were more limited in their activities one year and five years later than those without limited shoulder range of motion. The association between shoulder pain at discharge and activities and participation five years later was also studied. This analysis showed that presence of shoulder pain at discharge was, surprisingly, not associated with limitations in activities and participation five years later.

DISCUSSION

Body structures; the AC joint

Our comparative study, presented in Chapter 2, of persons presenting with shoulder pain in an outpatient orthopedics clinic, showed a higher prevalence and degree of AC joint arthrosis in persons with SCI (98%) as compared to non-SCI persons with shoulder pain (92%).¹ After controlling for age and gender, the odds of having an increasingly severe arthrosis for persons with SCI was found to be nearly four times higher.

Our study showed a higher prevalence of AC joint arthritis than what has been found in former studies assessing this topic (see for detailed overview Appendix 1). This difference in

prevalence is likely related to specific study characteristics. Boninger et al. (2003)² found an overall prevalence of 30% in a population that included persons with paraplegia with and without shoulder pain, who were of younger age, and had a shorter TSI (i.e. 11.5 years) as compared to our population. Akbar et al. (2011) found a 42% prevalence of AC joint arthritis in persons with SCI and 26% in able-bodied persons.³ This study also included only persons with paraplegia with a shoulder pain prevalence of 67%. Similar to our study, Akbar et al. (2011) found a higher prevalence of shoulder pathology in persons with SCI compared to persons without SCI when controlling for age. Lal et al. (1998)⁴ studied changes in shoulder X-rays in 53 shoulders of wheelchair users and found the AC joint to be primarily affected. Finally, Medina et al. (2011)⁵ found that persons with a tetraplegia had a smaller AC joint compared to persons with a paraplegia, which the authors hypothesized to be related with a limited ROM.

Mercer et al. (2006) studied kinetic and kinematic data in 33 subjects with paraplegia as they propelled their wheelchair.⁶ Shoulder joint forces and moments were calculated using an inverse dynamic model and shoulder pathology was evaluated using a physical exam and magnetic resonance imaging scan. They found that specific joint forces and moments were related to measures of shoulder pathology. Persons who displayed larger lateral forces or abduction moments were more likely to have coraco-acromial (CA) ligament thickening. Higher BMI was associated with a higher odds ratio (OR) to develop changes of the AC joint and the CA ligament.

In conclusion, based on our study and current evidence in literature it seems that the AC joint in persons with SCI is more severely affected compared to non-SCI persons with shoulder pain. This is likely caused by the high burden on the shoulder from manual wheelchair propulsion and other wheelchair-related activities such as transfers and weight-relief maneuvers. Manual wheelchair propulsion has shown to be particularly straining, placing high total forces on the shoulder, especially during the push phase.⁷ Besides, wheelchair propulsion requires an internal rotation of the shoulder,⁸ changes in scapula position⁹ and an increased forward lean of the upper body, especially during fatigue,⁸ which increases the risk of impingement syndrome. Also, everyday activities sitting in the wheelchair require many overhead activities, like reaching, which is a risk factor for the development of impingement syndrome.¹⁰ Finally, weight-reliefs and/or transfers put a high load on the shoulder complex.¹¹⁻¹⁵

Body functions; shoulder pain

In Chapter 3 in this thesis, we studied the prevalence and trajectories of shoulder pain, and its determinants up to five years after inpatient rehabilitation.

Prevalence of shoulder pain and course over time

A 43% prevalence of musculoskeletal shoulder pain in the total group of the Umbrella and SPIQUE studies was found at start of active rehabilitation, 50% three months later, 40% at discharge, 34% one year after discharge and 42% five years after discharge.¹⁶ Based on data of 225 persons with SCI included in the Dutch Umbrella Study, three distinct musculoskeletal shoulder pain trajectories were identified in the period between the start of active SCI rehabilitation and five years after discharge: a 'High pain' trajectory, a 'No or Low pain' trajectory and a 'Decrease of pain' trajectory. We hypothesized that we would also identify a fourth trajectory with an increase of shoulder pain. Both the 'High pain' and 'No or Low pain' trajectory showed a slight tendency for an increase in musculoskeletal shoulder pain between one and five years after discharge, but no distinct 'Increase of pain' trajectory could be identified. We assume that a longer follow-up is needed in order to show the effects of what might be called 'accelerated ageing' (for example arthrosis) of the shoulder in persons with SCI.

The prevalence of shoulder pain in persons with SCI in other studies varies widely (for specific numbers of available studies, see Appendix 2). Mean shoulder pain prevalence during the acute phase after SCI was found to be around 48% (range 3–100) and 50% (range 3–85) in the chronic phase after SCI.^{4, 6, 17-60} This broad range is probably due to the differences in study population and the time of assessment. Most previous studies on shoulder pain in SCI utilized a cross-sectional study design in persons with chronic SCI, used different definitions of shoulder pain, used different outcome measures and/or included different populations and TSI. Therefore, comparisons with the prevalence of shoulder pain in our study should be interpreted with caution. The longitudinal study of Ballinger et al. (2000) included a convenience sample of 89 men with SCI (both tetraplegia and paraplegia) who were measured at two time points. At the first measurement these men had an average age of 37 years (range 19–77 years) and a mean TSI of 10 years (range 1–48 years). The second measurement was three years after entering the study. At the second measurement this group showed a 30% prevalence of shoulder pain.¹⁹ A prospective cohort study by Salisbury et al. (2003, 2006)^{46, 47} was conducted in 41 persons with a tetraplegia during first inpatient rehabilitation with a follow-up after two and four years.^{46, 47} They found an 85% prevalence of shoulder pain in persons with tetraplegia during the acute phase after SCI.

In our study the 'High pain' trajectory, mainly existing of persons with tetraplegia showed similar prevalences (90% at start, 73% at 3M, and 78% at 1Y). After four years Salisbury et al. found a shoulder pain prevalence of 70%, which is higher compared to what was found after five years in our study population (51%). The higher prevalence of shoulder pain in the study of Salisbury et al. could be due to the fact that they included only persons with a tetraplegia. A recent study of Zanca et al. (2013) showed a 22.6% prevalence of shoulder pain at admission, 19.1% at discharge from first rehabilitation and 44.9% during rehabilitation.⁶⁰ This lower prevalence might be explained by the fact that pain was abstracted from nursing pain sheets and therefore the pain prevalence is assumed to be underreported (not all patients might spontaneously report shoulder pain to the nurse, especially when it is mild or moderate). Several studies addressed shoulder pain in persons with childhood onset SCI56 or spina bifida,^{23, 31, 49, 58} and found lower prevalence of shoulder pain. Although it is assumed that the human body in childhood SCI adapts better to the new weight-bearing tasks of the shoulder, the exact mechanism and concomitant anatomical and kinematic changes are currently unknown.

Determinants of shoulder pain

Although significant differences in group characteristics between the three shoulder pain trajectories existed when using bivariate analysis, based on multiple logistic regression our current study identified only two significant predictors of belonging to the 'High pain' trajectory (as compared to the 'No or Low pain' trajectory): 1) having a tetraplegia and 2) having a limited passive shoulder ROM.¹⁶ The other included factors that were expected to be possible predictors (i.e. age, TSI, completeness of the injury, presence of shoulder pain before SCI, obesity and spasticity) were not significant in the final multiple logistic regression analyses. In previous literature different factors associated with shoulder pain in SCI have been described. In recently published studies, older age,^{18, 29, 31, 35, 46, 56, 57} longer TSI,^{21, 31, 32, 35, 38, 50} higher BMI,⁵⁵ lesion level (tetraplegia),^{26, 39, 46, 52, 55, 59} muscle strength (inversely related),⁵⁵ longer duration of bed rest⁴⁶ and functional outcome (inversely related)^{55, 56} were related to higher shoulder pain scores. However, as mentioned before, most of the described findings above are based on studies in persons with chronic SCI using a cross-sectional design, and should therefore be interpreted with caution.

The 'Decrease of pain' trajectory only existed of 14 persons, and was therefore not included in the multivariate analyses. In the bivariate analysis, the 'Decrease of pain' trajectory was not significantly different from the 'High pain' trajectory with regard to level of injury and shoulder ROM, but participants in the 'High pain' trajectory were significantly more

often obese, had a lower manual muscle testing score and suffered more frequently from spasticity.

The 'High pain' trajectory consisted mainly of persons with a tetraplegia, which might originate in the impaired muscles balance of the shoulder complex. For persons with a tetraplegia, manual wheelchair driving and (learning) other tasks during initial rehabilitation are assumed to be more straining on the shoulder as compared to persons with a paraplegia.

Body functions; shoulder ROM

Prevalence and course over time of shoulder ROM limitations

In Chapter 4 we described that, in the participants of the Umbrella Study, limitations in shoulder ROM were present in up to 70% of the persons with SCI. The highest risk of limitations in shoulder external rotation emerged in the inpatient rehabilitation, while limitations in shoulder flexion limitation were most prominent one year after inpatient rehabilitation. In up to 26% (95% CI: 20–37) of the subjects in limitations in shoulder ROM were found in both shoulders.

Studies on the prevalence of shoulder ROM limitations in persons with SCI are scarce. The only other longitudinal study on shoulder ROM performed by Diong et al. (2012) in 92 persons with SCI (both tetraplegia and paraplegia) found, during the first year after injury, a prevalence of shoulder ROM limitations of 43%, which is comparable to our findings.²⁸

All other studies addressing shoulder ROM had a cross-sectional design. Comparison of these studies to our results should be made with caution. The prevalence of shoulder ROM limitations in these cross-sectional studies is found to range between 9 and 43%. Daylan et al. (1999) described a prevalence of only 9% of shoulder ROM limitations during the acute phase in a retrospective medical record study,²⁷ which is likely to have led to underreporting. Ballinger et al. (2000) found ROM problems in 22% of a group of 89 men with long-term traumatic SCI (45% paraplegia, TSI: average 10 years, range 1–48 years).¹⁹ Finally, Sinnott et al. (2000) found a 43% prevalence of limited ROM in both shoulders among 42 persons with long-term paraplegia.⁵²

In conclusion, shoulder ROM limitations (mainly external rotation) is assumed to be a significant problem, already appearing during first rehabilitation, while only a minority of the persons with shoulder ROM limitation shows improvement of shoulder ROM limitations in the first year after rehabilitation. The first measurement time point in the Dutch Umbrella

Study was performed at start of initial rehabilitation. We assume that during the acute phase, interventions to preserve shoulder ROM such as mobilization of the shoulders, might not be sufficient and more attention for preservation of shoulder function and health during the acute phase is needed.

Determinants for shoulder ROM limitations

In Chapter 4 of this thesis we described that in the study population of the Dutch Umbrella Study, risk factors for shoulder ROM limitations included having a tetraplegia, older age, spasticity of elbow muscles, a longer TSI at start of active rehabilitation and presence of shoulder pain.⁶¹

The only other prospective study of Diong et al. (2012), which assessed shoulder ROM did not analyze determinants for shoulder ROM limitations due to the small study size.²⁸

In our study, having a tetraplegia was shown to be the most important risk factor for shoulder ROM limitations during and one year after rehabilitation (presented in Chapter 4). At and above the level of C5, shoulder muscles are increasingly impaired, resulting in an imbalance of shoulder musculature. In the literature, this imbalance is often postulated to be the cause of shoulder pain and ROM problems in wheelchair-dependent persons.^{51,}

⁵⁷ Although problems with shoulder ROM are considered to be a complication of SCI, older age may contribute to the increased prevalence and severity of shoulder problems in SCI. Furthermore, older age was found to be a risk factor for limited shoulder ROM. However, some studies show that in persons with SCI, degenerative changes are not solely a problem of older age, but might occur already at a younger age compared to persons without a SCI.¹ Finally, prolonged immobilization was shown to be a risk factor for shoulder ROM limitations in the present study,⁶¹ highlighting the importance of early mobilization and proper shoulder positioning, which will be discussed in the section on 'Clinical implications'. Spasticity of the elbow flexors was found to increase the risk for developing limited shoulder flexion for the right shoulder only. Daylan et al. (1999) found a positive association between use of spasticity requiring medication and ROM limitations which indicates that spasticity may play a role in the development of shoulder ROM limitations.²⁷ Based on the experience of several Dutch and Swiss clinicians working with persons with SCI, in daily practice spasticity of the m. biceps brachii is found to cause the most problems in shoulder ROM and is often treated with oral medication or local medication like botulin toxin injections. Spasticity of the m. triceps brachii in daily practice seems less often a reason for treatment. In our study, spasticity of the elbow extensors was found to be related to an increased risk for all measured shoulder ROMs in both shoulders.

A reason for this finding might be that spasticity of the elbow extensors was less severe in the study population. Considering the measurement of spasticity an important remark should be made: definition and measurement of spasticity in SCI is complex. Definitions of spasticity in SCI vary with the physiological prejudices of the definer, but patients (and inexperienced clinicians) often sum stiffness, muscle pain, and spasms to one single clinical problem.⁶² Since spasticity is multidimensional, focusing on one or two spasticity outcome measures can misrepresent the extent and influence of spasticity on SCI patients. A review of different scales showed that these measure different aspects of spasticity and correlate weakly with each other. Spasticity may be better measured with an appropriate battery of tests, including the Ashworth Scale (AS) or Modified AS, along with the Penn Spasm Frequency Score (PSFS). These tools would benefit from further reliability and responsiveness testing. Currently, tools that assess the influence of spasticity on patient activities, participation and quality of life are important, but lacking.⁶³

In contrast to the literature,^{19, 58, 64} in our study female gender was not shown to be a risk factor for limitations of shoulder ROM. Finally, Daylan et al. (1999) found that persons with a pressure ulcer, requiring medication for spasticity and co-existent head injury were more likely to have contractures (no specification for the shoulder was given).²⁷ These factors were not included in our analyses but might be important variables to consider in future studies.

So far, our study is the largest study on shoulder ROM limitations in persons with a SCI and the first to study the course over time and analyzing determinants of shoulder ROM limitations. The early development of contractures of the shoulder reaffirms the importance of immediate involvement of Physical Medicine and Rehabilitation (PM&R) physicians in the acute phase of SCI and of early admission to a specialized SCI center.

Shoulder impairment & associations with activities and participation

The studies presented in Chapter 5 and 6 showed that persons with SCI included in the Umbrella and SPIQUE studies and had limited shoulder ROM at discharge performed worse on activities one year later, as measured with the FIM-Motor Score, the ability to make a transfer independently and the time score of the wheelchair circuit. This association was not found in the subsample of persons with tetraplegia. No significant association was found between a limited shoulder ROM and participation, as measured with the PASIPD. At five years after discharge, shoulder ROM at discharge, but not shoulder pain, was associated with a lower ability to make an independent transfer, a lower FIM-Motor Score and a lower likelihood to have employment for at least one hour per week.

Other studies that investigated the relation between shoulder ROM and/or shoulder pain in SCI are cross-sectional and therefore comparison of our results is limited. Ballinger et al. (2000), who studied the relationship of shoulder pain and shoulder ROM limitations in a cross-sectional sample of 89 adult men with traumatic SCI living in the community showed that subjects with chronic SCI and a limitation in shoulder ROM were more likely to need maximal assistance for transfers and reported a lower FIM score.¹⁹ They showed that although shoulder pain was unrelated to functional outcome measures, it was negatively related to the mean score on the Craig Handicap Assessment and Reporting technique (CHART). The relation of shoulder pain with limitations in activities and participation was studied by Salisbury et al. (2003, 2006) in a cross-sectional study (survey) design in 27 subjects with a tetraplegia 2–4 years post-injury.^{46, 47} They showed that shoulder pain was related to specific activities (as measured with the Wheelchair User's Shoulder Pain Index) and showed that presence of shoulder pain was inversely associated with QOL. Unfortunately, this study did not investigate the association of shoulder pain with participation. The survey performed by Gutierrez et al. (2005) on shoulder pain among 80 wheelchair-dependent persons with chronic SCI (mean duration of SCI 20 years) reported that shoulder pain was associated with reduced physical activity (lower PASIPD scores), while they did not find an association between shoulder pain and community activities.³⁶ Regression analysis was not performed and therefore it remains unknown whether the relation would hold taking into account confounders.

In our total group, as well as in those participants with tetraplegia, we found a significant difference in the amount of time needed for wheelchair tasks between those with and without limited shoulder ROM. However, after controlling for confounding factors we only found a significant association between a limited shoulder ROM and the time needed for the wheelchair circuit items only in the total group, and not for persons with a tetraplegia. A possible explanation for this outcome might be the small sample size (N=52) of the subgroup with tetraplegia.

In our study shoulder pain at discharge was not associated with limitations in activities and restrictions in participation five years later. A reason for this lack of association might be that shoulder pain influences activities and participation only in very severe cases. Our clinical experience is that persons with shoulder pain present themselves only with severe shoulder complaints and with significant structural changes (which makes it more difficult to treat patients with conservative and/or preventive interventions). This is confirmed by the study on AC joint arthrosis in persons with SCI (Chapter 2), which showed that persons with SCI tend to present themselves with a more advanced stage of AC joint arthritis compared

to able-bodied persons.¹ Another reason for not finding an association between shoulder pain and activities and participation might be because persons with severe shoulder pain were excluded from the maximal exercise test and wheelchair circuit, which could have resulted in an underrepresentation of persons with severe shoulder pain in these tests and the subsequent subset in the analyses. This might also have influenced the results of the study and be the reason for not finding significant associations between shoulder ROM nor shoulder pain at discharge with POpeak and performance of time of the wheelchair circuit. An additional explanation for the lack of association between shoulder pain and participation is that participation might more strongly be influenced by other factors; for example, having an adapted car or the person's motivation to be physically and/or socially active.^{65, 66}

METHODOLOGICAL CONSIDERATIONS

The Dutch Umbrella and SPIQUE studies resulted in a comprehensive and successful study. However, the results of the studies presented in this thesis should be interpreted within the scope of the study design.

The considerations and limitations of the study on AC joint arthrosis were included in Chapter 4 and will not be discussed here again.

The study population (whom to measure)

In the Umbrella Study 'Restoration of mobility in spinal cord injury rehabilitation' (and therefore also in the SPIQUE study) only persons aged between 18 and 65 years with an expected permanent wheelchair dependency were included. Elderly persons (>65 years) were excluded from the study, which influences the generalizability of the study outcomes to the elderly population. It might be expected that in elderly persons with SCI shoulder problems might be a more prominent problem due to age-related degenerative changes of the shoulder.⁶⁷

Furthermore only persons with sufficient understanding of the Dutch language, without progressive disease, and without major psychiatric problems were included in the study. This also might have influenced the generalizability of the study.

Choice of measurement times (when to measure)

The main aim of the Umbrella Study, to describe and analyze the restoration of mobility during rehabilitation, implied that the inpatient rehabilitation, as intervention, is a determinant for mobility. This assumption resulted in the decision to measure participants during their inpatient rehabilitation from the start of active rehabilitation onwards (when they were able to sit four or more hours in a wheelchair). This choice was made to assure that persons were able to participate in the clinical tests of the study like the wheelchair skills test and wheelchair exercise test. The second measurement time was performed three months later and the third measurement was performed at discharge. As such, time modeled as a continuous variable in the Dutch Umbrella and SPIQUE studies (in contrast to a study design for instance takes time since injury (days) as starting point), which should be taken in mind when interpreting the study results. A strength of the multicenter study is that we were able to measure a relatively large group of patients relatively quickly after SCI with a prospective design and fairly long follow-up.

In the Dutch Umbrella Study we did not assess the etiology of shoulder pain by clinical exam or radio-diagnostics. Adding this in future studies would give us better insight into the potentially different patho-physiological mechanisms of shoulder pain among persons with tetraplegia and paraplegia.

Comparability of studies/what and how to measure

The ICF bio-psychosocial model was the conceptual basis for the Umbrella and SPIQUE studies. The ICF categories used within the context of this thesis are mentioned in the introduction of this thesis. Due to the various measurement instruments used in studies comparison of study outcomes is difficult. Meanwhile, initiatives to increase comparability between studies were taken by the ICF Research Branch by creating the ICF Core Sets for SCI^{68,69} and the International Spinal Cord Injury Association (ISCoS) by creating SCI Data Sets (www.iscos.org.uk). The possibility to link measurement instruments to their ICF categories, has improved comparability between study outcomes.⁷⁰⁻⁷² The ISCoS initiative to create the International Data Sets for SCI and ICF to create the Core Sets for SCI intends also to improve the comparability between studies. Some choices made regarding the included ICF categories and outcome measures in the Umbrella Study and the SPIQUE study, for example the assessment of pain, do not conform to the ICF Core Sets for SCI or to the ISCoS recommendations, simply because they were not available at the time.

A final consideration should be made regarding the assessment of rehabilitation interventions during and after first inpatient rehabilitation. Within the Umbrella study, although initially considered, no assessment of rehabilitation treatment and therapies was made due to the lack of feasibility in Dutch rehabilitation practice at the start of the study. Knowledge about the relationships between the needs of the patients, the rehabilitation interventions provided and the rehabilitation outcomes achieved is essential. Without this knowledge, we cannot identify effective treatments or improve the quality of treatments provided. The development of the Spinal Cord Injury-Interventions Classification System⁷³⁻⁷⁷ and the SCIRehab⁷⁸⁻⁸⁵ has provided us now with valuable classification systems to assess rehabilitation interventions. These classification systems give us the opportunity to analyze dose-response relations, compare therapy provided during inpatient rehabilitation between patients or subgroups of patients (e.g., tetraplegia, paraplegia, traumatic or non-traumatic, younger and older patients), in identifying the interventions having the greatest impact on outcomes, and in improving effective and efficient clinical decision-making based on more than just 'expert opinion'.^{83, 86}

Multicenter research

In the Umbrella Study and SPIQUE studies, all eight rehabilitation centers with a specialized SCI ward in the Netherlands participated. These centers are, as mentioned in the introduction, united by the DUFCoS (former NVDG on www.nvdg.nl). This assures to some extent that the rehabilitation process in these centers is uniform, i.e. following the same guidelines. But rehabilitation is 'people's work' and differences in the treatment among centers will always be present. Furthermore, each center had its own research assistant and physician to perform the measurements. Much effort was given to define strict guidelines for each measurement, and a continuous training was performed for the research assistants (and physicians) through regular common meetings over the year. In the multilevel analyses, we corrected for possible differences among the study centers, which eventually did not show to influence the outcomes.

Missing data and use of (new) statistical methods

Missing data are unavoidable in longitudinal epidemiological and clinical studies. The main question that has to be answered is whether the loss to follow-up influences the results of the study. In the Dutch Umbrella and SPIQUE studies, mainly persons with a tetraplegia and older age were lost to follow-up.⁸⁷ Tetraplegia showed to be an important predictor for shoulder

ROM limitations and shoulder pain and therefore we should be aware that the presented results might underestimate the real problem of shoulder ROM limitations and shoulder pain.

During the last decades new bio-statistical methods were rapidly developed. Examples include the introduction of multi-level analyses and methods for repeated measures, as well as the ability to take into account missing data and/or systematic variance between centers and research assistants. Some of these (new) methods have been applied in the studies included within this thesis. In the study on the development of shoulder ROM limitations,⁶¹ using random coefficient analyses, it was possible to include all present persons at each measurement time, which provided us with realistic data on the occurrence of shoulder ROM limitations during each interval. Insight into the course of problems with shoulder ROM was guaranteed by the longitudinal design of the study. This contributes to the understanding of the problem. In the study on shoulder pain trajectories we used latent class growth mixture modeling (LCGMM).¹⁶ LCGMM is a contemporary longitudinal technique based on structural equation modeling, incorporating both latent (unobserved) variables. For the LCGMM, missing data were handled according to the Expectation-Maximization Algorithm (EM-Algorithm).^{88,89} Although statistically sound, this algorithm assumes data to be missing at random. This assumption is unfortunately difficult to test and we therefore cannot rule out that the group lost to follow-up is 'not random' and could have influenced our outcomes. Although we assumed that our lost to follow-up group was not random (more elderly were lost to follow up or did not participate in the physical tests), a sensitivity analysis found no clear indications that this was the case.

Implementation of new statistical methods in rehabilitation research might improve research quality. A close cooperation between researchers, clinicians, epidemiologist and (clinical) statisticians is prerequisite to producing statically sound and meaningful outcomes.

CONSIDERATIONS FOR FUTURE RESEARCH

Study design

Seeking an evidence base for rehabilitation medicine, or conscientious, explicit use of current best evidence in making decisions about the care of individual patients and practice, is probably as old as medicine itself.

As shown in the introduction of this thesis, shoulder problems are complex and multifactorial. Although the current thesis adds to the understanding of the development,

course over time, determinants of shoulder problems and the association with activities and participation, many gaps in our understanding on the etiology and structural changes of the shoulder after SCI still exist. Some studies have already shown that persons with childhood onset of SCI⁵⁶ have less shoulder problems as those with adult onset SCI, which might suggest that the human shoulders are capable of successful adaption to wheelchair propulsion at a young age. The nature of the differences in structure, function as well as skill-related indices and underlying mechanisms require our future research attention.

The Dutch Umbrella study measured first at start of active rehabilitation when patients were already admitted to the rehabilitation center. Furthermore no specific shoulder exam was performed and no additional diagnostics were performed such as biomechanical/kinematical measurements of propulsion or transfers and their associated mechanical loading on the shoulder, nor ultrasound examinations, plain radiographs or magnetic resonance imaging (MRI) of the shoulder structure. To understand the development and patho-physiology, there is need for further longitudinal studies starting early after SCI, including clinical shoulder examination and additional diagnostics.

Intervention studies, especially in rehabilitation research, are difficult to conduct, due to the limited numbers of patients with SCI, the heterogeneity of the study populations, costs and difficulty to perform blinded studies. Until today a few high quality intervention studies have been performed, most of them in persons with chronic SCI who already have shoulder problems (Appendix 3).^{26, 90-104}

Vegter et al. (2013) studied the mechanical efficiency and propulsion technique during the initial stage of motor learning and found that able-bodied participants significantly increased their mechanical efficiency and changed their propulsion technique from a high frequency mode with a lot of negative work to a longer-slower movement pattern with less power losses.¹⁰⁵ Propulsion technique was shown to relate to mechanical efficiency. These findings link propulsion technique to mechanical efficiency and support the importance of a correct propulsion technique for wheelchair users. A possible intervention study could be to test different training techniques, measure the mechanical efficiency and propulsion technique and follow-up on shoulder problems and wheelchair skills during first rehabilitation. Several studies showed a benefit of exercise therapy during chronic SCI.^{90, 92, 93, 98, 99, 101, 102, 106} Since shoulder problems seem to develop already in the early stage after SCI, an intervention study focusing on the prevention of shoulder problems with a specific (low intensity) exercise program such as is implemented in the multicenter study 'Active Lifestyle Rehabilitation interventions in aging spinal cord injury (ALLRISC)'^{107, 108} or

a specific shoulder exercise program (muscle power, proprioception and coordination of the shoulder muscles before persons start wheelchair propulsion) would be a logical next step in research.

Furthermore, hand-cycling was shown to be a less straining mode of exercise and transportation in sports, recreation and wheeled mobility.^{7,109} Arnet et al. (2012) compared the shoulder load during hand-cycling and wheelchair propulsion under similar conditions of external power in persons with spinal cord injury. They found that due to continuous force application in hand-cycling, shoulder load was lower compared with wheelchair propulsion.¹⁰⁹ In another study by Arnet et al. (2013) the external applied forces, the effectiveness of force application and the net shoulder moments of hand-cycling in comparison with hand-rim wheelchair propulsion at different inclines were analyzed. They found that the resulting peak net shoulder moments were lower for hand-cycling compared with wheelchair propulsion at all inclines.⁷ These results confirm the assumption that hand-cycling is physically less straining. Therefore, hand-cycling seems to be an alternative for mobility in persons with SCI. However, although Valent et al. (2010) found no adverse effects of handcycle-training on the shoulder in a 12 week period,¹¹⁰ the long-term effects of hand-cycling on shoulder problems, have not yet been studied and could be a valuable aim of future studies.

Finally, based on the results of this thesis it would be interesting to study the effects of shoulder mobilization in the acute phase, early after SCI, paying attention not only to shoulder external rotation and abduction, but also to preserve shoulder flexion by, for example scapula stabilization and mobilization and balanced muscle training.

Comprehensive studies

To understand shoulder problems in persons with SCI future epidemiological research requires a more comprehensive approach. The ICF Core Sets for SCI could be a basis for this comprehensive approach.^{68,69} A longitudinal study that addresses shoulder ROM and relates it to pain, structural changes and ageing will provide more insight into the cause and development of limitations of shoulder ROM. Future studies ideally should not only address shoulder ROM and shoulder pain, but also structural changes (by radio-diagnostics of the shoulder), changes in body functions (e.g. muscle power, spasticity), activities (e.g. transfers, wheelchair driving) and participation (for example: work, social contacts), and should assess aids (type of wheelchair, sitting position), environmental factors (use of medication, wheelchair design, aids and adaptations), personal and psychological characteristics (for example coping strategy) and kinematic analyses of wheelchair propulsion. Although

understanding basic shoulder biomechanics has been improved by musculoskeletal modeling. These models estimate internal loading on the human skeleton from external measurements like kinematics and external forces; so far these internal forces cannot be directly measured in vivo in persons with a SCI.^{7, 12-15, 109, 111-115} In addition, the measurement of biomechanics and kinematics have not been implemented in, or combined with, epidemiological studies so far and would be an important addition to rehabilitation-based study designs.

Sample size considerations

Larger international studies (multicenter studies) are needed to be able to show relevant associations of, for example, lesion level within the paraplegic group (high level paraplegics versus low level paraplegics), and to study the role of posture and trunk stability on the development of shoulder pain.

Duration of follow-up

The duration of the Umbrella and SPIQUE studies have now reached a five year follow-up after inpatient rehabilitation. Two shoulder pain trajectories show an increasing trend between one and five years after SCI. To show whether this increase is relevant, and might retrieve a fourth 'Increase of pain' trajectory, a follow-up measurement of studies at, for example, 10 years and beyond is needed. Comprehensive cross-sectional studies, like the SwiSCI Cohort Study¹¹⁶ and ALLRISC^{117, 118} study are important to provide us with data on prevalence of shoulder problems in different age groups and at different TSI.

In summary, the results of the current study and (lack of) available evidence show that there is a need for larger (international) comprehensive longitudinal studies with a longer duration of follow-up, a role for intervention studies and a need for standardization of outcome measurements.

CONSIDERATIONS FOR CLINICAL PRACTICE

With the increased life expectancy of persons with SCI and the wish for quality of life¹¹⁹ the shoulder joint has to stay healthy for a longer period of time. Independence in mobility is for many patients and health professionals of utmost importance during rehabilitation. To assure healthy aging and independence, prevention of shoulder problems should be a continuous lifelong focus of attention.

Health professionals (and insurances) should stay critical in how we best treat persons with a SCI and continuously scrutinize what the short-term and long-term hazards and benefits are of applied interventions and aids. Choosing an alternative mode for mobility that is less straining for the shoulder, like hand-cycling, should be considered for all patients. Applying assistive devices for transfers and adaptations to the car for carrying the wheelchair in the car should be applied where needed. Optimizing wheelchair design, adjusted to the individual needs of the patient, with optimizing the ergonomics and mechanics, tire type and tire pressure¹²⁰ should be warranted in each patient with SCI during initial rehabilitation and be checked during routine yearly check-ups over the life-span.

Mobilization, training and education

Although regaining independent mobility is for many patients (and health professionals) of utmost importance, patience is needed to train the (remaining) muscles of the upper body and allow them to adapt to their new tasks and prevent overuse injuries. Overuse of the shoulder could lead to damage of the structures of the shoulder and may therefore lead to limited shoulder ROM.^{1-3, 5, 6, 19, 22, 121-123} The training of the upper extremities and how to use the shoulder during tasks, such as wheelchair propulsion,¹⁰⁵ low-intensity training,¹⁰⁷ transfers, household activities, sports etc. should be a goal during rehabilitation. Patients should be (made) aware that training of the upper extremities is a lifelong challenge and should be educated how to best train and use their shoulders in daily life and prevent overuse injuries.

In the acute phase optimal shoulder positioning and early (passive and active) mobilization of the shoulder joint is important since prolonged shoulder immobilization is found to contribute to limited shoulder ROM.^{57, 61}

Furthermore, we should be aware that patients with shoulder problems tend to refer themselves late to a health professional. During yearly checkups, shoulder problems should be explicitly asked about and patients should be instructed to present themselves in an early stage with shoulder problems in a SCI-specialized rehabilitation clinic.

Wheelchair design, aids and alternative modes for mobility

An optimal wheelchair design is prerequisite for the prevention of shoulder problems. An important factor for shoulder functioning and functional end-level is the role of postural control.⁵² This is often seen in the choice of wheelchair design (without trunk stabilization)

and striving for independent transfers and manual wheelchairs, even in persons with tetraplegia. We should ask ourselves whether these choices, in the context of shoulder problems, are justified on the long-term.

Even if the wheelchair is optimally designed, hand-rim wheelchair propulsion has shown to be straining for the shoulder, inefficient and ineffective.⁷ Alternatives for the wheelchair, like the hand bike, the Swiss track and power-assisted wheels, shown to be less straining⁷ and should be considered as alternative modes of mobility in an early phase by health professionals and insurances. Furthermore, patients should be instructed to check pressure of the tires regularly (and this should be checked at each clinical visit).

Other straining tasks for the shoulder complex are transfers and weight-relief lifts.^{12-14, 92, 124, 125} Weight-reliefs as prevention for pressure sores are suggested in literature and in daily practice often applied by patients.¹²⁶⁻¹²⁸ However, only very few studies have evaluated the effect of weight-reliefs on the development of pressure sores. Level 3 evidence exists for the effectiveness of weight-reliefs. (www.scireproject.com). Weight-reliefs must be sustained for 1–2 minutes to raise tissue oxygen to unloaded levels. Level 4 evidence exists to support position changes to reduce pressure at the ischial tuberosities (www.scireproject.com). The limited evidence for these weight-reliefs should make health professionals at least critically question whether or not these pressure reliefs should be performed in every person and which technique we want to instruct our patients. Furthermore, since transfers have been shown to be extremely straining on the shoulders,^{12, 13} persons with SCI should be taught optimal transfer techniques with (if needed) help of persons or assistive devices. Last, some activities might be best avoided like, for example transporting the wheelchair in the car without assistive devices, which is a very straining activity and can be (easily) solved with car adaptations.

Monitoring and measurement in daily practice

Although elements of current clinical practice are evidence based, there remains much room for improvement. Important new evidence from research often takes a long time to be implemented in daily care (for example the advice of the Consortium of Spinal Cord Medicine on pressure reliefs at www.scicpg.org), while established practices persist even if these practices have been shown to be ineffective or harmful (e.g. as mentioned already above: inappropriate performed weight-reliefs).

Monitoring and measurement of shoulder problems and the interface with wheelchair set-up is needed to understand the complex etiology of shoulder problems in persons with SCI.

The early development of shoulder ROM limitations and shoulder pain in some patients shows that active monitoring (measuring) of patients should start during rehabilitation in order to find patients at risk at an early stage. Initiatives like the Wheelchair Expert Evaluation Laboratory (Wheel-i) that includes evaluations of the patient by health professionals and researchers should be considered.¹²⁹

After discharge the annual visits in the SCI-specialized rehabilitation centers should be used to re-evaluate shoulder status from a comprehensive approach, including a medical check-up, analysis of wheelchair propulsion and transfer technique, wheelchair status and need for adaptive devices. During first rehabilitation and during follow-up check-ups, at the very least, clinicians should ask questions regarding presence, severity (with the numeric rating scale), localization and type of shoulder pain. The use of the International Basis Pain Data Set for SCI¹³⁰ ensures continuity and comparability between measurements, needed for clinical follow-up of the patient, but also ensures comparability between centers, needed for scientific purposes. If shoulder pain is present at least the Wheelchair Users Shoulder Pain Index (WUSPI) should be assessed.^{131, 132} The clinical exam should include neurological level and completeness of SCI (AIS score), a proper examination of the neck and shoulder including inspection, palpation (trigger point), measurement of active and passive shoulder ROM (including the scapula), assessment of upper extremity and upper-body muscle power (MRC) and assessment of spasticity (if possible with EMG) of the upper extremities. Health professionals should be aware that besides SCI-specific shoulder problems, also common and uncommon pain syndromes may be present in persons with SCI, such as avascular necrosis of the glenohumeral joint, subdeltoid bursitis, deltoid syndrome, scapulocostal syndrome, os acromiale pain syndrome, glomus tumor of the shoulder, suprascapular nerve entrapment and qaurilateral space syndrome and referred pain from the neck, spine and brachial plexus.^{133, 134}

The results of our study on AC joint arthrosis presented in Chapter 2 indicated that persons with SCI tend to present and are diagnosed with an advanced stage of AC joint arthrosis as compared to able-bodied persons with shoulder pain.¹ This again shows the need for routine assessment during yearly check-ups over the life-span with consideration of radio-diagnostic imaging (Ultrasound, plain X-ray and when necessary MRI). This comprehensive assessment of shoulder function starting shortly after SCI and across the life-span is needed to diagnose shoulder problems at an early stage in order to intervene successfully and try to maintain healthy ageing in persons with spinal cord injury.

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Appendix 1 Overview of literature on studies on structural changes of the shoulder after spinal cord injury. References are listed in chronological order of date of publication.

Author	Year	N	Acute SCI/ chronic SCI	Study design	Outcome	Results
1 Wylie et al. ¹	1988	38 TP/PP (ns)	Chronic	Retrospective chart review	Degenerative changes of shoulder joint	Lower activity associated with shoulder degeneration.
2 Campbell et al. ²	1996	24 TP/30 shoulders	Chronic	Cross sectional	X-ray changes	Instability/impingement/RCT/capsulitis and other.
3 Lal ³	1998	53 shoulders SCI level ns)	Acute/ chronic	Cross sectional	X-ray changes	AC joint primarily affected. Radiological changes associated with higher level of wheelchair activity/higher age and female gender.
4 Escobedo et al. ⁴	1997	64 PP	Chronic	Cross sectional	MRI	In all patients with PP 57% showed RCT. In symptomatic patients with SCI 73% showed RCT, in symptomatic AB 59%. RCT in PP was mainly found posterior and prevalence and severity correlates with age and TSI.
5 Ballinger et al. ⁵	2000	22 PP	Chronic	Longitudinal	X-ray changes	GH and AC-joint changes. Esp. persons with ROM problems had AC-joint narrowing.
6 Boninger et al. ⁶	2001	28 PP	Chronic	Cross sectional	X-ray/ MRI changes	X-ray: subacromial spur/RC enthesitis/AC-joint DJD/distal clavicular osteolysis. MRI: Distal clavicle edema, AC joint changes/osseous spur/Enthesial edema/CA ligament edema/CA ligament thickening.
7 Boninger et al. ⁷	2003	14 PP	Chronic	Intervention study/wheelchair propulsion speed	MRI changes	Women, radial force direction related to worsening of MRI score. No effect of BMI, age, TSI.

8	Mercer et al. ⁸	2006	33 PP	Chronic	Cross sectional/ clinical exam	MRI changes	Higher directional shoulder forces and moments associated with MRI changes. Higher BMI associated with higher or to develop MRI changes AC-joint and CA ligament.
9	Van Drongelen et al. ⁹	2007	11 TP/21 PP/2 non-SCI	Chronic	Cross sectional	Biceps tendon changes in US	After exercise acute changes in the biceps tendon were found (edema). Patients with shoulder pain showed lower echogenicity.
10	Ruckstuhl et al. ¹⁰	2007	11 PP/8 TP/9 AB	Chronic	Cross sectional	MRI changes of humeral cartilage	Mean humeral thickness and minimal joint space did not differ between groups. Superior thickness PP>TP.
11	Kivimäki and Ahoniemi ¹¹	2008	AB 103/54 PP 54/TP 66	Chronic	Cross sectional	Ultrasound changes	SCI level associated with edema of GH joint.
12	Brose et al. ¹²	2008	TP 14/PP 35	Chronic	Cross sectional	Ultrasound changes	All shoulders examined exhibited abnormalities on ultrasound.
13	Akbar et al. ¹³	2010	100 PP/100 AB	Chronic	Matched control	MRI	RCT 63% in PP, 15% in AB.
14	Medina et al. ¹⁴	2011	7 PP/9 TP	Chronic	Cross sectional	X-ray changes	TP smaller AC-joint.
15	Eriks-Hoogland et al. ¹⁵	2012	49 PP/9 TP/105 AB	Chronic	Retrospective	MRI diagnosis AC joint arthrosis	SCI patients presenting with shoulder pain showed similar prevalence, yet more advanced AC joint arthrosis than able-bodied patients.

AB = Able bodied; AC joint = Acromio-clavicular joint; BMI = Body Mass Index; CA = Coracoid acromion; GH joint = Gleno-humeral joint; MRI = Magnetic Resonance Imaging; Ns = not specified; PP = Paraplegia; RC = Rotator cuff tear; RCT = Rotator cuff tear; SCI = Spinal cord injury; TP = Tetraplegia; US = Ultrasound.

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Appendix 2 Overview of research literature on studies of prevalence of shoulder pain and shoulder range of motion after spinal cord injury and relation with activities and participation (References are listed in chronological order of date of publication)

Author	Year	n	Acute SCI/ chronic SCI	Study design	% of persons with shoulder pain	Determinants for shoulder pain	Shoulder ROM limitation (%)	Determinants for limited shoulder ROM	Relation to activities/ participation
1 Ohry et al. ¹	1978	5 TP/4 PP	Acute/ chronic	Case series	All	-	-	-	-
2 Nichols et al. ²	1979	652 SCI (ns)	Chronic	Cross sectional/ Survey	51.4	-	-	-	Pain mainly during wheelchair usage, transfers.
3 Silverskiold et al. ³	1986	40 TP/20 PP	Acute (till 18 months)	Cross sectional/ Clinical screening	In first 6 months: TP 87, PP 35/At 18 months: TP 33, PP 30	-	-	-	Shoulder pain had no relation to functional disability in PP, but in TP (with spasticity).
4 Bayley et al. ⁴	1987	94 PP	Chronic	Clinical series	33 (during transfer)	-	-	-	-
5 Gellman et al. ⁵	1988	84 PP	Chronic	Cross sectional/ Clinical screening	67.8	TSI	-	-	-
7 Frisbie et al. ⁶	1990	66 SCI (ns)	Acute/ chronic	Cross sectional/ Interview	3	-	-	-	-
8 Waring et al. ⁷	1991	52 TP	Acute (till 6 months)	Retrospective medical record study	57	Older age, limited shoulder ROM, no PT in first 2 weeks	-	-	-

Appendix 2 continues on next page

Appendix 2 Continued

Author	Year	n	Acute SCI/ chronic SCI	Study design	% of persons with shoulder pain	Determinants for shoulder pain	Shoulder ROM limitation (%)	Determinants for limited shoulder ROM	Relation to activities/participation
9 Penland and Twomey ⁸	1991	11 PP/11 AB	Chronic	Cross sectional/ Survey/clinical testing	73	-	-	-	Pain mainly during wheelchair propulsion, transfers.
10 Sie et al. ⁹	1992	139 PP/103 TP	Chronic	Cross sectional/ Interview	TP 46/PP 36	TSI	-	-	-
11 Burnham et al. ¹⁰	1993	187 PP/1 Polio/1 spina bifida/20 AB	Chronic	Cross sectional/ clinical exam	PP 26 diagnosed with pain in RC syndrome test	Impingement syndrome	-	-	Pain as sign of RC syndrome. PP with RC syndrome weaker adduction, external and internal rotation.
12 Gerhart et al. ¹¹	1993	98 TP/18 PP	Chronic	Cross sectional/ survey	-	-	-	-	Pain (not specified to shoulder pain) was associated with needing more help.
13 Pentland and Twomey ¹²	1994	52 PP	Chronic	Cross sectional/ Survey and clinical testing	60	TSI	-	-	Pain was related to work/school, transfers, outdoor wheeling, driving.
14 Aisen and Aisen ¹³	1994	43 TP	Chronic	Retrospective medical record study	C3-C5 100 C4-C7 75				Study on shoulder hand syndrome.

15	Subbarao et al. ¹⁴	1995	TP 198/103 PP	Chronic	Cross sectional/ Survey/clinical exam	72.2	No relation with age, neurological level and TSI	-	-	Pain most prevalent during wheelchair propulsion and transfer.
16	Campbell and Koris ¹⁵	1996	24 PP (30 shoulders	Acute/ chronic	Clinical exam/ radiology	All (inclusion criteria)	-	-	-	Acute: RCT/ ant. instability, impingement/ osteoarthritis/ osteonecrosis. Chronic: ant. instability, multidirectional instability, capsular contracture/capsulitis.
17	Lall ¹⁶	1998	53 SCI (ns)	Acute/ chronic	Cross sectional/ Clinical exam/ radiology	11	-	-	-	Radiological changes associated with higher level of wheelchair activity/ higher age and female gender. AC joint primarily affected.
18	Curtis et al. ¹⁷	1999	92 TP/103 PP	Acute/ chronic	Cross sectional/ Survey	Since SCI: TP 78.3/ PP 59.2/ Current: TP 7/PP 41.7	TP	-	-	-
19	Dalyan et al. ¹⁸	1999	62 TP/68 PP	Chronic	Cross sectional/ Survey	71	-	-	-	Pain related to pressure reliefs, transfers and wheelchair mobility.

Appendix 2 continues on next page

Appendix 2 Continued

Author	Year	n	Acute SCI/ chronic SCI	Study design	% of persons with shoulder pain	Determinants for shoulder pain	Shoulder ROM limitation (%)	Determinants for limited shoulder ROM	Relation to activities/participation
20 Curtis and Black ¹⁹	1999	18 SCI (total n included 46%)	Chronic	Cross sectional/ Survey	Of total n: 72 since wheelchair use/current use/52	Ns: health condition, age, TSI, hours sport/leisure/wheelchair use	-	-	Persons with SCI did not report more often pain as persons with other health conditions.
21 Noreau et al. ²⁰	2000	207 TP/275 PP	Chronic	Cross sectional/ Survey	24	complete lesion	-	-	Secondary impairments related to perceived health status, personal income.
22 Ballinger et al. ²¹	2000	89 SCI (ns)	Chronic	Longitudinal/ Survey, X-ray	30	ROM limitations	22%	Male gender, longer TSI, AC joint narrowing, lower FIM score, poorer health	ROM associated to lower CHART scores and lower perceived health.
23 Boninger et al. ²²	2001	28 PP	Chronic	Cross sectional/ survey and clinical exam	30	Lower activity level ns: body weight, TSI, age, imaging abnormalities	-	-	

24	Turner et al. ²³	2001	194 TP/97 PP/2 ns	Chronic	Cross sectional/ Survey	76 since SCI/ current 69	-	-	-	Moderate interference with activities.
25	Widerström-Noga et al. ²⁴	2001	118 TP/ PP with chronic pain	Chronic	Cross sectional/ Survey	30–39.9	TP	-	-	-
26	Sinnot et al. ²⁵	2001	22 PP	Chronic	Survey	82	Higher level of injury	-	-	-
27	Vogel et al. ²⁶	2002	123 TP/93 PP	Chronic	Cross sectional/ Interview	48	Association with older age, no association with degree of neurological impairment and FIM score	-	-	21% of the persons with shoulder pain reported limitations in activities.
28	Salisbury et al. ²⁷	2003	41 TP	Acute	Prospective/ Survey/clinical exam	85	Age <30 years or >50 years, C2–C5 lower AIS motor score, shorter duration of bed rest	During rehabilitation pain group lost shoulder ROM	Shoulder pain, previous shoulder injury	No relation pain and functional skills at discharge.
29	Fullerton et al. ²⁸	2003	174 SCI (ns)/83 spina bifida, amputation or ns	Chronic	Cross sectional/ Survey	39 in athletes/ 66 in non-athletes:	Non-athletes, higher age, longer TSI, Higher level	-	-	% invulen.

Appendix 2 continues on next page

Appendix 2 Continued

Author	Year	n	Acute SCI/ chronic SCI	Study design	% of persons with shoulder pain	Determinants for shoulder pain	Shoulder ROM limitation (%)	Determinants for limited shoulder ROM	Relation to activities/participation
30 Samuels-son et al. ²⁹	2004	89 PP	Chronic	Cross sectional/ Survey and clinical exam	37.5	Muscular atrophy, impingement, tendinitis, wheelchair activity	-	-	No correlation with activity and participation, COPM pain associated with 52 problems with occupation with performance.
32 Gironda et al. ³⁰	2004	770 PP	Chronic	Cross sectional/ Survey	83 since SCI/ current 67.1	Wheelchair related mobility and transportation activities. No relation with TSI, age.	-	-	-
33 Liem et al. ³¹	2004	TP 143/ PP 181	Chronic	Cross sectional/ tel. interview	11.6 upper extremity joint problems	-	11.6% upper extremity joint problems	-	Upper extremity problems not related with need for more help in ADL.
34 Jensen et al. ³²	2005	147 SCI (ns)	Chronic	Cross sectional/ longitudinal/ Survey	Last week: 38/ last month 58 60.7	Longer TSI (exclusive of age)	-	-	Especially pain during ADL. Patients with pain reported lower SF 36 score and lower score on social integration. ns: productive activity and home competency.

35	Van Drongelen et al. ³³	2006	TP 60/PP 100	Acute/chronic	Longitudinal/ Survey	TP max 58/ PP max 26	TP, lower FIM, lower muscle strength of UE, pain at beginning rehabilitation, higher BMI	-	-	-
36	Sawatzky et al. ³⁴	2005	22 adult P/31 Spina bifida	Chronic	Cross sectional	Mean WUPSI in adult PP>spina bifida (% ns)	Age ns. TSI ns.	-	-	In adult PP 36% reported limitations in sports due to shoulder pain. No pain while lifting wheelchair into the car.
37	Dudley-Javoroski and Shields ³⁵	2006	2 TP/ 8 PP	Chronic	Cross sectional/ Survey	>50	-	-	-	-
38	Salisbury et al. ³⁶	2006	27 TP	Chronic	Longitudinal/ Survey	70	C6-T1	Intensity worse by movement and cold weather	-	Related to daily tasks and inverse related to QOL.
39	Mercer et al. ³⁷	2006	33 PP	Chronic	Cross sectional/ clinical exam	30 during clinical exam	Higher directional shoulder forces and moments	not specified, mean physical exam score 1.03 (max12)	-	-

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Appendix 2 Continued

Author	Year	n	Acute SCI/ chronic SCI	Study design	% of persons with shoulder pain	Determinants for shoulder pain	Shoulder ROM limitation (%)	Determinants for limited shoulder ROM	Relation to activities/participation
40 McCasland et al. ³⁸	2006	63 SCI (ns)	Chronic	Cross sectional/ Survey	70	TP, higher SPADI, previous shoulder trauma, less use of trapeze bars.	-	-	Pain associated with higher SPADI.
41 Gutierrez et al. ³⁹	2007	80 SCI (ns)	Chronic	Cross sectional	100 (inclusion criteria)	-	-	-	Shoulder pain intensity related to lower QOL and lower physical activity scores. No relation to community activities.
42 Alm et al. ⁴⁰	2008	101 PP	Chronic	Cross sectional/ Survey	40	Age	-	-	Intensity of pain highest during pushing up ramps or inclines.
43 Brose et al. ⁴¹	2008	49 TP	Chronic	Cross sectional	24.5	Shoulder noise during activity	-	-	
44 Eriks-Hoogland et al. ⁴²	2009	77 TP/122 PP	Acute/ chronic	Longitudinal/ Survey/clinical exam	-	-	70%	Older age, spasticity of elbow, longer TSI at start rehab, shoulder pain.	

45	Gupta et al. ⁴³	2010	236 PP/40 ns	Chronic	Cross sectional/ Survey	4.7 (shoulder and upper limb)	Age/TS/ ambulation	-	-	Pain negatively associated with QOL.
46	Jain et al. ⁴⁴	2010	93 SCI (ns)	Chronic	Cross sectional/ Survey	39.8	Use of assistive devices	-	-	Pain also present in motorized wheelchair users and crutch users.
47	Eriks- Hoogland et al. ⁴⁵	2011	31 TP/115 PP	Acute/ Chronic	Longitudinal/ Survey and clinical exam	-	-	39%	-	Limited shoulder ROM was associated with lower FIM motor score, longer time for wheelchair skills and independence in transfers 1 year later.
48	Diong et al. ⁴⁶	2012	92 SCI (ns)	Acute	Longitudinal/ clinical exam	-	-	43%	-	-
49	Pellegrini et al. ⁴⁷	2012	47 PP	Chronic	Retrospective medical record study and Cross sectional study	65.9	-	-	-	-
50	Eriks- Hoogland et al. ⁴⁸	2013	134 PP/91 TP	Acute/ Chronic	Prospective cohort study	43 at start of active reha- bilitation, 50 3 months later, 40% at discharge, 34 1 year after discharge and 42 5 years after discharge	Persons with a TP and limited shoulder ROM had higher chance to belong to high pain trajectory	-	-	-

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Appendix 2 Continued

Author	Year	n	Acute SCI/ chronic SCI	Study design	% of persons with shoulder pain	Determinants for shoulder pain ROM	Shoulder ROM limitation (%)	Determinants for limited shoulder ROM	Relation to activities/participation
51 Zanca et al. ⁴⁹	2013	1357 SCI (ns)	Acute	Longitudinal	22.6 on admission, 19.1 at discharge, 44.9 during rehab.	-	-	-	Patients with pain spend fewer days in rehabilitation, received less rehabilitation in hours.
52 Wessels et al. ⁵⁰	2013	12 PP3 amputation, 5 spinal cord injury, 1 CP3 myelitis, 6 other	Chronic	Cross sectional	47 of total group	No effect of age, TSI, weight and sex and amount of wheelchair use per day.	Not defined	Pain negative effect on ROM. Sex (Males smaller ROM)	-
53 Eriks-Hoogland et al. ⁵¹	Submitted	47 TP, 91 PP	Acute/ Chronic	Prospective cohort study	At discharge 54	-	At discharge 44	-	Limited ROM but not pain at discharge was associated with limitations in activities and participation.

AB = Able bodied; AC joint = Acromio-clavicular joint; BMI = Body Mass Index; CA = Coracoid acromion; CHART = Chraig Handicap Assessment and Reporting Technique; CP = Cerebral palsy; GH joint = Gleno-humeral joint; MRI = Magnetic Resonance Imaging; ns = not specified; PP = Paraplegia; PRP = Platelet rich plasma; QOL = Quality of life; RA = Rheumatoid Arthritis; RC = Rotator cuff; RCT = Rotator cuff tear; ROM = Range of motion; SCI = Spinal cord injury; SPADI = Shoulder Pain and disability Index; SRQ = Shoulder Rating Questionnaire; SII = Social Interaction Inventory; TP = Tetraplegia; TSI = Time since injury; MS = Multiple sclerosis; WUSPI = Wheelchair Users Shoulder Pain Index.

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Appendix 3 Summary of current research literature on intervention studies on shoulder problems after spinal cord injury. References are listed in chronological order of date of publication.

Author	Year	n	Acute SCI/ chronic SCI	Study design	Outcome	Intervention and Follow-up time in weeks	Result
1 Curtis et al. ¹	1999	42 (25 SCI)	Chronic	RCT/ Standard exercise protocol	Pain	24 weeks	Seventy-five per cent of the subjects reported a history of shoulder pain since beginning wheelchair use. The average initial performance-corrected (PC-WUSPI) score of the 42 subjects was 17.7 (± 21.3) with a range of 0-103.2 points. Over 83% of the subjects (35 of 42) completed the 6-month study. Subjects in the treatment group decreased their PC-WUSPI score by an average of 39.9%, compared to decreases of only 2.5% in the control group.
2 Dyson-Hudson ²	2001	18	Chronic	Acupuncture/Trager therapy	Pain	5 weeks intervention and 5 weeks post treatment	Mean PC-WUSPI scores decreased significantly during the treatment period in both the acupuncture (53.4%; 23.3 points) and Trager (53.8%; 21.7 points) treatment groups. The reduced PC-WUSPI scores were maintained in both groups throughout the 5-week post treatment follow-up period.
3 Panagos et al. ³	2004	5 TP/3 PP	Chronic	Case series/ Magnetic fields	Pain	Pre-/post treatment (0 weeks)	The short-form McGill Pain Questionnaire descriptors demonstrated significant decreases: stabbing, 0.75 ± 0.71 ($p < 0.02$); sharp, 0.50 ± 0.53 ($p < 0.033$); and tender, 0.88 ± 0.83 ($p < 0.021$). They also demonstrated a significant decrease in the present pain intensity of 0.63 ± 0.52 ($p < 0.011$). Participants demonstrated a nonsignificant decrease of 0.813 ± 0.998 ($p < 0.55$) on the visual analog scale. Pressure algometry was nonsignificant with a difference of 0.062 ± 1.17 ($p < 0.885$).

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Appendix 3 Continued

Author	Year	n	Acute SCI/ chronic SCI	Study design	Outcome	Intervention and Follow-up time in weeks	Result
4 Nawoczenki et al. ⁴	2006	Intervention: 3 TP, 18 PP Control: 19 PP, 1 spina bifida	Chronic	Case control study/ Exercise	Pain	8 weeks	Subjects in the intervention group showed significant improvements in all measures (WUSPI from 43 to 20 and SRQ from 66 to 82) as a result of the intervention, whereas asymptomatic control group subjects remained stable.
5 Nash et al. ⁵	2007	7 PP	Chronic	Case series/ Resistance training	Pain	16 weeks	Intervention group significant reduction in WUSPI.
6 Dyson-Hudson et al. ⁶	2007	6 TP/11 PP	Chronic	RCT/Acupuncture	Pain	5 weeks treatment, 5 weeks follow- up	Shoulder pain (WUSPI) decreased significantly over time in both the acupuncture and the sham acupuncture groups ($p=0.005$), with decreases of 66% and 43%, respectively. There was no significant difference between the 2 groups ($p=0.364$).
7 Finley et al. ⁷	2007	10 PP/1 spina bifida/1 post-polio/1 stroke/1 spinal stenosis/1 RA/1 ataxia	Chronic	Test retest/2-speed geared wheel	Pain	20 weeks	There was significant reduction in shoulder pain (WUSPI) after the intervention at week 2 ($p=0.004$) through week 16 ($p=0.015$). The difference was not found at week 20; however, 1 participant reported an increase in pain from unrelated factors during week 20. Change from baseline was calculated without this subject's data; there was a significant reduction in shoulder pain ($p=0.003$).
8 Dyson-Hudson et al. ⁸	2007	10 TP/13 PP	Chronic	Uncontrolled/Arm crank ergometer exercise	Pain	12 weeks	n.s. change in WUSPI.

9	Giner-Pascual et al. ⁹	2011	45 PP	Chronic	Uncontrolled/ Transdermal nitroglycerine (NT)	Pain	24 weeks	NT treatment reduced the awareness of shoulder pain and increased the functional movement and range of articular motion in the shoulders of the experimental group members ($p<0.05$). Shoulder pain (WUSPI) decreased to one third (48 to 16) of baseline levels after the intervention in the exercise/movement optimization group, but remained unchanged in the attention control group (42 to 40). Shoulder torque, SF 36 scores and QOL scores improved.
10	Mulroy et al. ¹⁰	2011	80 PP	Chronic	RCT/Exercise	Pain	16 weeks	In the experimental group, there significant changes were found for WUSPI scores, $F(2, 50)=29.80$, $p<0.001$; SII scores, $F(2, 50)=3.77$, $p=0.03$; and QOL scores, $F(2, 50)=7.82$, $p=0.001$. Decreases in pain were associated with increases in social participation and QOL.
11	Kemp et al. ¹¹	2011	58 PP	Chronic	RCT/Exercise	Pain	16 weeks	Comparison of baseline and 8-week data demonstrated significant change in the noninjected shoulder on USPRS score ($Z=2.207$, $p=0.027$), in PESS score ($Z=2.120$, $p=0.034$), and in the VAS pain score ($Z=2.041$, $p=0.041$).
12	Ibrahim et al. ¹²	2012	8 SCI (ns)	Chronic	Case series/Platelet Rich Plasma (PRP)	Pain	8 weeks	For those with musculoskeletal pain ($n=5$), median pain intensity ratings improved from 4 at baseline to 0 at the end of study.
13	Norrbrink et al. ¹³	2012	5 PP	Chronic	Case series/ Exercise	Pain	10 weeks	Improvement of WUSPI and ROM external/internal ratio higher/ flexion/extension ration lower.
14	Serra-Añó et al. ¹⁴	2012	15 PP	Chronic	Uncontrolled/ Exercise	Pain/ROM	8 weeks	

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Appendix 3 Continued

Author	Year	n	Acute SCI/ chronic SCI	Study design	Outcome	Intervention and Follow-up time in weeks	Result
15 Rice et al. ¹⁵	2013	3 TP/24 PP	Acute	RCT: Wheelchair Education Protocol Based on Practice Guidelines for Preservation of Upper-Limb Function versus standard care	Pain	At the time of discharge from inpatient rehabilitation and at 6 months and 1 year postdischarge. (>52 weeks)	Participants in the intervention group pushed on tile with significantly lower push frequency ($p=0.02$) at the discharge visit. On the ramp, the intervention group used a significantly larger push length ($p=0.03$) across all time points. No significant differences were found between groups related to wheelchair setup, selection, pain, satisfaction with life, and participation.
16 Hubert et al. ¹⁶	2013	5 TP/5 PP	Chronic	Case series/Service dog	Pain	30 weeks	Using a service dog significantly decreased shoulder pain (WUSPI 65 to 46) and the intensity of the effort made, generated slight improvements in MWC mobility and social participation, and may have indicated a trend toward improved quality of life and increase of distance covered.
17 Rice et al. ¹⁷	2014	37 SCI		RCT: Education Protocol Based on Practice Guidelines for Preservation of Upper-Limb Function versus standard care	Pain	Untill 1 year post-training	No significant changes in pain score.

AB = Able bodied; AC joint = Acromio-clavicular joint; BMI = Body Mass Index; CA = Coracoid acromion; CHART = Chraig Handicap Assessment and Reporting Technique; GH joint = Gleno-humeral joint; MRI = Magnetic Resonance Imaging; Ns = not specified; n.s. = not significant; PP = Paraplegia; PRP = Platelet rich plasma; QOL = Quality of life; RA = Rheumatoid Arthritis; RC = Rotator cuff tear; RCT = Rotator cuff tear; ROM = Range of motion; SCI = Spinal cord injury; SPADI = Shoulder Pain and disability Index; SRQ = Shoulder Rating Questionnaire; SII = Social Interaction Inventory; TP = Tetraplegia; TSI = Time since injury; MS = Multiple sclerosis; WUSPI = Wheelchair Users Shoulder Pain Index.

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SUMMARY

“The challenge is Healthy Ageing: growing older in a healthy and active way. Maintaining good health well beyond pension age would greatly enhance quality of life and well-being, as well as labour participation, informal care capacity and other significant contributions to society. However, new knowledge is required about the influence of these factors, and how they interact with one another.”

(Quote: Healthy Ageing Campus Netherlands at
<http://www.healthyageingcampus.nl/about/healthy-ageing>)

Subject of this thesis was one of the dominant health issues in persons with a spinal cord injury, namely shoulder pain and limitations in shoulder range of motion and its consequences on performance of activities and participation.

A spinal cord injury results in muscle weakness or paralysis, loss of sensation and loss of autonomic function below the level of the lesion. After a spinal cord injury, approximately 80% of the persons remain wheelchair-dependent and rely on their upper extremities for mobility and daily tasks. As such, it is not surprising that shoulder pain and limitations in shoulder range of motion are common among persons with spinal cord injury. The mean prevalence of shoulder was found to be approximately 50% during both the acute and chronic phase after spinal cord injury. The mean prevalence of range of motion limitations was approximately 30% and 40%, respectively. Although it has been suggested that shoulder pain might negatively affect activities and participation, as well as quality of life, the association of passive shoulder range of motion limitations and shoulder pain with activities and participation is only scarcely studied and the literature shows conflicting results. Therefore the (mechanism of the) development of shoulder problems and their course over time in persons with spinal cord injury were unclear at the start of the study. To improve goal setting and to optimize intervention programs in in- and outpatient rehabilitation and follow-up care, the aim of the present thesis was: 1) to gain understanding in structural changes, prevalence and the course of shoulder problems (pain and range of motion) over time and, 2) to study the complex association between aspects of shoulder structure, shoulder function and activities and participation using the International Classification of Functioning, Disability and Health as a framework.

In **chapter 1** an overview of the context of the thesis was given. A short description of the health condition ‘spinal cord injury’, its epidemiology has been presented. Afterwards, an overview of the most important secondary health conditions in persons with spinal cord

injury was presented. Third, the consequences of a spinal cord injury on functioning were explained, introducing the bio-psychosocial model of the International Classification of Functioning, Disability and Health. Following was a description of the functional anatomy of the shoulder complex, the current understanding of shoulder impairment in persons with a spinal cord injury and the association of shoulder pain and shoulder range of motion with activities and participation in spinal cord injury are described. After a short description of medical and rehabilitation care in the Netherlands and Switzerland, the research context of this thesis was described, namely the Dutch prospective cohort study 'Restoration of mobility in spinal cord injury rehabilitation', also called 'the Umbrella project', and its follow-up study the 'Spinal cord injury QQuality of life Evaluation (SPIQUE)' project, the Swiss Paraplegic Research and the Swiss Paraplegic Centre. Finally, a detailed outline with aim, research objectives and research questions of this thesis was presented.

Body structures: the acromioclavicular joint

In **chapter 2** we have presented a study performed at the Swiss Paraplegic Research and Swiss Paraplegic Centre, in which we have compared prevalence, severity and risk of acromioclavicular joint arthrosis in persons presenting with shoulder pain with and without a spinal cord injury.

We performed a retrospective analysis of medical records of 68 persons with spinal cord injury and 105 able-bodied persons with shoulder pain and evaluated magnetic resonance images collected in the outpatient orthopaedics clinic. We found that the overall prevalence of acromioclavicular joint arthrosis was 98% for persons with spinal cord injury and 92% for able-bodied persons. In both groups, acromioclavicular joint arthrosis was frequently accompanied by diagnosis of rotator cuff tears and biceps tendon ruptures. Sensitivity of clinical testing was found to be low in spinal cord injury (0.31) as well as in able-bodied persons (0.23) with shoulder pain. The odds of increasingly severe arthrosis was nearly 4 times higher in persons with spinal cord injury compared to able-bodied persons ($p=0.0001$). The analysis of arthrosis severity in the spinal cord injury-group revealed, after controlling for the effects of sex and age, a weak association with time since injury and no association with level or completeness of the lesion.

We concluded that persons with spinal cord injury and shoulder pain showed similar prevalence, yet more advanced acromioclavicular joint arthrosis than able-bodied persons with shoulder pain. This is likely caused by the high burden on the shoulder from manual wheelchair propulsion and other wheelchair-related activities such as transfers and weight-

relief maneuvers. Since early diagnosis of arthrosis is a prerequisite for the initiation of successful conservative interventions of shoulder deterioration, we recommend routine assessment of shoulder status including diagnostic imaging during check-ups.

Body functions: shoulder pain

Although shoulder pain is a problem in the majority of persons with spinal cord injury, so far no studies have empirically identified longitudinal patterns (trajectories) of musculoskeletal shoulder pain after spinal cord injury. Therefore the aim of **chapter 3** was: 1) to identify distinct trajectories of musculoskeletal shoulder pain in persons with spinal cord injury, and 2) to determine possible predictors of these trajectories.

We studied a multicenter prospective cohort of 225 newly injured persons with spinal cord injury in the Netherlands (participants of the Umbrella and SPIQUE studies).

Shoulder pain was assessed on five occasions: at start of active rehabilitation, three months later, at discharge, at one year and five years after discharge. Latent class growth mixture modeling was used to identify the distinct shoulder pain trajectories.

We identified three distinct shoulder pain trajectories: a 'No or Low pain' trajectory (64%), a 'High pain' (30%) trajectory, and a trajectory with a 'Decrease of pain' (6%). Compared with the 'No or Low pain' pain trajectory, the 'High pain' trajectory consisted of more persons with tetraplegia, shoulder pain before injury, limited shoulder range of motion, lower manual muscle test scores, or more spasticity at start of active rehabilitation. Multivariate logistic regression analysis showed two significant predictors for the 'High pain' trajectory (as compared with the 'No or Low pain' trajectory): having a tetraplegia (odds ratio (OR) = 3.2; $p=0.002$) and having limited shoulder range of motion (OR=2.8; $p=0.007$). Surprisingly, we did not find an 'Increase of pain' trajectory. One of the reasons might be that an increase of pain due to degenerative causes may present at later age and after longer time since injury. Therefore, a study with longer follow-up is needed.

Body functions: shoulder range of motion

Since literature regarding prevalence and course over time of shoulder range of motion is scarce, we have investigated the prevalence and course of passive shoulder range of motion in people with spinal cord injury and analysed the relationships between shoulder range of motion limitations and personal and lesion characteristics. The results of this study were presented in **chapter 4**.

A total of 199 participants with a new spinal cord injury were included in the Dutch multicentre Umbrella study. We assessed shoulder range of motion at the start of active rehabilitation, three months later, at discharge and one year after discharge. We found a limited shoulder range of motion ($\geq 10^\circ$) in up to 70% (95% CI: 57–81) of the subjects with tetraplegia and in 29% (95% CI: 20–38) of those with paraplegia during or in the first year after inpatient rehabilitation. Shoulder flexion was mostly affected. Up to 26% (95% CI: 20–37) of the participants had bilateral shoulder range of motion limitation. We found that a limited shoulder range of motion is common following spinal cord injury and that tetraplegia, increased age, spasticity of elbow extensors, longer duration between injury and start of active rehabilitation and presence of shoulder pain increased the risk of limited shoulder range of motion.

Activities and participation: associations with shoulder range of motion and shoulder pain

In **chapter 5** we have described the results of the study on the relation between limited shoulder range of motion at discharge in 146 participants with spinal cord injury on the performance of activities, wheeling performance, transfers and participation one year later. We assessed shoulder range of motion at discharge from first rehabilitation and assessed the Functional Independence Measure (FIM)-Motor Score, the ability to transfer, the Wheelchair Skills Test (WST) and the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) one year later. Possible confounding factors were age, gender, level and completeness of injury, time since injury and shoulder pain. Data were analysed for the total group (both paraplegia and tetraplegia) and for the subgroup of persons with tetraplegia.

We found that participants with limited shoulder range of motion at discharge had a worse independence on FIM-Motor Score and were less likely (total group 5 times, participants with tetraplegia 10 times less likely) to perform an independent transfer one year later. In the total group, participants with limited shoulder range of motion needed more time to complete a 15 meter sprint and figure-of-eight in the wheelchair. In both groups no significant associations with the level of physical activity (PASIPD) were found.

In **chapter 6** we have presented the results of the study analyzing the association of musculoskeletal shoulder pain and limitations in shoulder range of motion at discharge from first rehabilitation and activities and participation five years later in 138 participants of the Umbrella and SPIQUE studies. The main outcome measures used in this study were Peak exercise performance, WST, FIM-Motor Score, ability to transfer, PASIPD, Mobility Range and Social Behavior scales of the Sickness Impact Profile 68 (SIPSOC) and employment status.

We found that shoulder range of motion limitations, but not shoulder pain, was bivariately associated with all but one outcomes at 5 years. After correcting for confounders (personal and lesion characteristics) shoulder range of motion limitation at discharge showed to be negatively associated with the ability to transfer independently FIM-Motor Score, and return to work 5 years later. No significant associations were found with Peak exercise performance, performance of time of the WST, the PASIPD and SIPSOC.

Finally, in **chapter 7** the main findings of the thesis were summarized and discussed in the context of the scientific literature. Subsequently, we have discussed some of the methodological considerations related to the study design and its implications for the interpretation and generalizability of the study results. We have given, based on our results, available literature and clinical experience, recommendations for future research, like performing studies with a comprehensive approach, including kinematics and diagnostic imaging, the use of uniform outcome measures and discussed the role and content of intervention studies.

Finally, based on our results, available literature and clinical experience, we have given recommendations for clinical practice. In the acute phase optimal shoulder positioning and early (passive and active) mobilization of the shoulder joint should be warranted. The training of the upper extremities and how to use the shoulder during tasks should be focus during rehabilitation. Patients should be (made) aware that training of the upper extremities is a lifelong challenge and should be educated how to best train and use their shoulders in daily life and prevent overuse injuries. Optimizing wheelchair design, adjusted to the individual needs of the patient, with optimizing the ergonomics and mechanics, tire type and tire pressure should be warranted in each patient with SCI. Choosing an alternative mode for mobility that is less straining for the shoulder, like hand-cycling, should be considered for all patients. Applying assistive devices for transfers and adaptations to the car for carrying the wheelchair in the car should be applied where needed. We have recommended to establish a life-long comprehensive follow-up of shoulder problems in persons with spinal cord injury, including medical anamneses and clinical examination and diagnostic imaging, but also including observation and kinematic analysis of wheelchair skills and performance and the assessment of current use of and need for adaptive devices like the wheelchair. This comprehensive assessment of shoulder function starting shortly after SCI and across the life-span is needed to diagnose shoulder problems at an early stage in order to intervene successfully and try to maintain healthy ageing in persons with spinal cord injury.

SAMENVATTING

“De uitdaging is Gezond Ouder worden: ouder worden op een gezonde en actieve manier. Het behoud van gezondheid tot op hoge leeftijd draagt bij aan een goede kwaliteit van leven en welzijn, maar ook aan participatie, zoals betaald werk, zorgen voor anderen en andere belangrijke bijdragen aan de maatschappij. Maar er is nieuwe kennis nodig over de invloed van deze factoren en over hoe ze met elkaar samenhangen.”

(Vertaling van Quote: Healthy Ageing Campus Netherlands at <http://www.healthyageingcampus.nl/about/healthy-ageing>)

Het onderwerp van dit proefschrift is een van de gezondheidsproblemen bij personen met een dwarslaesie, namelijk schouderproblemen en de gevolgen die deze schouderproblemen voor de uitvoering van activiteiten en participatie hebben.

Een dwarslaesie heeft naast verlies van spierkracht ook verlies van sensibiliteit en verstoring van de regulatie van het autonome zenuwstelsel tot gevolg. Na een dwarslaesie blijft ongeveer 80% van de personen rolstoelgebonden. Deze personen zijn van de bovenste extremiteiten afhankelijk voor de uitvoering van vrijwel alle dagelijkse activiteiten, zoals rolstoelrijden en het maken van transfers. Het is daarom niet verwonderlijk dat schouderpijn en beperkingen van de schouderbeweeglijkheid bij personen met een dwarslaesie vaak voorkomen. Op basis van de bestaande literatuur wordt geschat dat de prevalentie van schouderpijn in personen met een dwarslaesie in de acute en de chronische fase ongeveer 50% is. Voor beperkingen van de schouderbeweeglijkheid wordt de prevalentie op 30 tot 40% geschat. Hoewel in de literatuur de suggestie wordt gewekt dat schouderproblemen een negatieve invloed hebben op de uitvoering van activiteiten, participatie en kwaliteit van leven, is er maar weinig onderzoek gedaan naar deze relatie en zijn de resultaten en conclusies niet eenduidig. Dit had tot gevolg dat de ontstaanswijze, het beloop en de consequenties van schouderproblemen in personen met een dwarslaesie vooralsnog onvoldoende begrepen werden. Meer kennis over de ontstaanswijze, het beloop, de risicofactoren en de gevolgen van schouderproblemen was nodig om succesvolle preventie- en interventie maatregelen toe te kunnen passen.

Het doel van dit proefschrift was daarom: 1) het bestuderen van de structuur- en functieveranderingen, de prevalentie en het beloop van schouderproblemen bij personen met een dwarslaesie, met de focus op schouderpijn en de schouderbeweeglijkheid; 2) het bestuderen van de complexe samenhang tussen schouderproblemen, met name schouderpijn en

schouderbeweeglijkheid, en uitvoering van activiteiten en participatie. De 'International Classification of Functioning, Disability and Health (ICF)' werd gebruikt om deze complexe samenhang te modelleren.

In **hoofdstuk 1** hebben we de context van dit proefschrift beschreven. Na een beschrijving van de anatomie en fysiologische gevolgen van een dwarslaesie volgde een beschrijving van de epidemiologie. Vervolgens werd ingegaan op de meest voorkomende secundaire gezondheidsproblemen bij personen met een dwarslaesie. We hebben kort het bio-psychosociale model van de ICF beschreven, bedoeld als kader om de relatie tussen gezondheidsproblemen en functioneren te beschrijven en te bestuderen. Vervolgens hebben we de functionele anatomie van het schoudercomplex beschreven en de huidige kennis van schouderproblemen bij personen met een dwarslaesie. Hierbij hebben we ons gericht op schouderstructuren, schouderpijn, beperkingen van schouderbeweeglijkheid en de relatie met activiteiten en participatie.

We hebben een kort overzicht van de medische en revalidatiezorg in Nederland en Zwitserland gegeven met een korte beschrijving van de Nederlandse cohortstudie 'Herstel van mobiliteit in de dwarslaesierevalidatie', ook 'het Koepelproject' genoemd, en de vervolgstudie het 'Spinal cord injury QQuality of life Evaluation (SPIQUE)' project, het Zwitsers centrum voor dwarslaesieonderzoek (Swiss Paraplegic Research) en het Zwitsers dwarslaesiecentrum (Swiss Paraplegic Centre). Tot slot werden het doel en de onderzoeksvragen van dit proefschrift gepresenteerd.

Anatomische eigenschappen: het acromioclaviculaire gewricht

In **hoofdstuk 2** hebben we de resultaten van de studie gepresenteerd waarin we de anatomische afwijkingen van het acromioclaviculaire gewricht bij personen met een dwarslaesie vergeleken met een groep personen zonder dwarslaesie. Dit onderzoek werd uitgevoerd als samenwerkingsproject tussen het Zwitsers centrum voor dwarslaesieonderzoek en het Zwitsers dwarslaesiecentrum. We vergeleken de prevalentie, ernst en risicofactoren van artrose van het acromioclaviculaire gewricht tussen 68 personen met dwarslaesie en met schouderpijn en 105 personen zonder dwarslaesie maar met schouderpijn. Dit onderzoek was een retrospectieve studie waarbij persoonskenmerken (leeftijd, geslacht en tijd na het ontstaan van de dwarslaesie), gegevens over de dwarslaesie, klinische gegevens en MRI-diagnose werden beschreven en geanalyseerd.

De prevalentie van artrose van het acromioclaviculaire gewricht was 98% in personen met schouderpijn met een dwarslaesie en 92% in personen zonder dwarslaesie met schouder-

pijn. In beide groepen ging artrose van het acromioclaviculaire gewricht vaak gepaard met rotator cuff rupturen en rupturen van de bicepspees. De sensitiviteit van klinische schouder testen voor artrose van het acromioclaviculaire gewricht was in beide groepen laag (bij dwarslaesiepatiënten 0.32, bij personen zonder dwarslaesie 0.23).

De kans op een ernstige mate van artrose was in personen met een dwarslaesie bijna 4 keer zo hoog als voor personen zonder dwarslaesie met schouderpijn. De ernst van de artrose, na correctie voor geslacht en leeftijd, was matig gecorreleerd met de duur van de dwarslaesie en liet geen verband zien met hoogte en compleetheid van de dwarslaesie.

We concludeerden dat, hoewel de prevalentie van schouderartrose bij personen met een dwarslaesie en schouderpijn niet verschilt van die van personen zonder dwarslaesie en schouderpijn, de ernst van de artrose bij mensen met een dwarslaesie ernstiger is. Dit is waarschijnlijk het gevolg van de toegenomen schouderbelasting door rolstoelgebruik en andere ADL. Om artrose in een vroeg stadium te ontdekken en mogelijke preventieve en conservatieve maatregelen nog effectief in te kunnen zetten, was het advies om een routine-schouderonderzoek in te voeren tijdens de jaarcontrole met, indien nodig, aanvullend radiologisch onderzoek.

Funcities: schouderpijn

Hoewel schouderpijn bij de meerderheid van personen met een dwarslaesie voorkomt, wisten we nog maar weinig over het beloop en de mogelijk verschillende subgroepen in dit beloop (trajecten). Daarom hebben we in **hoofdstuk 3: 1** het beloop van schouderpijn en mogelijke verschillende trajecten, en 2) de mogelijke determinanten van deze schouderpijntrajecten onderzocht.

We hebben in een prospectieve studie 225 personen met een recente dwarslaesie (deelnemers van het Koepel- en SPIQUE project) onderzocht. Aanwezigheid en ernst van schouderpijn werd gemeten bij de start van actieve revalidatie, drie maanden later, bij ontslag, 1 jaar en 5 jaar na ontslag. Om de trajecten te identificeren pasten we 'Latent class growth mixture modelling' toe.

We vonden drie trajecten: een 'geen of weinig pijn' traject (64%), een 'veel pijn' traject (30%) en een 'afname van pijn' traject (6%). Vergeleken met de 'geen pijn' en 'afname van pijn' trajecten kenmerkte het 'veel pijn' traject zich door meer personen met een tetraplegie, aanwezigheid van schouderpijn voor het ontstaan van de dwarslaesie, beperkingen van schouderbeweeglijkheid, lagere spierkracht en meer spasticiteit bij start van de actieve revalidatie.

Multivariate logistische regressieanalyse liet twee voorspellers zien voor het 'veel pijn' traject ten opzichte van het 'geen of weinig pijn' traject, namelijk het hebben van een tetraplegie (odds ratio = 3.2; $p=0.002$) en het hebben van een beperkte schouderbeweeglijkheid (odds ratio = 2.8; $p=0.007$) bij start van de actieve revalidatie. Hoewel er een trend tot toename van schouderpijn lijkt in alle trajecten na de klinische revalidatie, vonden we tot onze verbazing geen 'toename van pijn' traject. Een reden dat we dit niet zagen is mogelijk de beperkte follow-up-duur van de studie. Een langere follow-up is dan ook aanbevolen voor vervolgonderzoek.

Functionies: schouderbeweeglijkheid

Er is weinig literatuur over de beperkingen en het beloop van schouderbeweeglijkheid over de tijd bij personen met een dwarslaesie. In **hoofdstuk 4** hebben we daarom de prevalentie van beperkingen van de schouderbeweeglijkheid en het beloop over de tijd in personen met een dwarslaesie en de relatie met persoons- en laesiekenmerken (hoogte en ernst van de laesie) onderzocht.

199 personen (deelnemers van het Koepelproject) met een recente dwarslaesie werden geïnccludeerd. De passieve schouderbeweeglijkheid werd op verschillende tijdstippen getest, bij start van actieve revalidatie, drie maanden later, bij ontslag uit het revalidatiecentrum, en een jaar na ontslag. We vonden dat in 70% (95% CI: 57–81) van de personen met een tetraplegie tijdens de revalidatie tot een jaar daarna een beperking van de schouderbeweeglijkheid van 10 graden of meer aanwezig was. Bij personen met een paraplegie was dit 29% (95% CI: 20–37). Met name schouderflexie bleek het meest frequent aangedaan. In 26% van de personen waren beide schouders aangedaan. Personen met een tetraplegie, hogere leeftijd, spasticiteit van de elleboogstrekkers, langere tijd sinds het ontstaan van de dwarslaesie en aanwezigheid van schouderpijn bleken een grotere kans op beperkingen van de schouderbeweeglijkheid te hebben.

Activiteiten en participatie: associatie met schouderbeweeglijkheid en schouderpijn

In **hoofdstuk 5** hebben we de resultaten van de studie naar de relatie tussen schouderbeweeglijkheid bij ontslag uit het revalidatiecentrum en de uitvoering van activiteiten, rolstoelvaardigheden, transfers en participatie een jaar later in 146 personen met een dwarslaesie (deelnemers Koepelproject) beschreven.

De schouderbeweeglijkheid werd bij ontslag uit het revalidatiecentrum gemeten en activiteiten (de Functional Independence Measure (FIM)-Motor Score, mogelijkheid een zelfstandige transfer uit te voeren, rolstoelvaardigheden (rolstoelvaardigheidentest) en de fysieke activiteit (Physical Activity Scale for Individuals with Physical Disabilities (PASIPD)) een jaar later. Confounders waren leeftijd, geslacht, niveau en compleetheid van de dwarslaesie, tijd sinds het ontstaan van de dwarslaesie en aanwezigheid van schouderpijn. De analyse werd uitgevoerd voor de totale groep (personen met een paraplegie en tetraplegie) en voor de subgroep van personen met een tetraplegie.

We vonden dat personen met een beperkte schouderbeweeglijkheid bij ontslag uit klinische revalidatie lager scoorden op de FIM-Motor Score en minder vaak (de totale groep 5 maal minder vaak, personen met een tetraplegie 10 maal minder vaak) een zelfstandige transfer uit konden voeren. In de totale groep hadden de personen met een beperking van de schouderbeweeglijkheid meer tijd nodig om een 15 meter sprint en een 8-figuur in de rolstoel uit te voeren. Er werden geen verschillen in de PASIPD-score gevonden tussen personen met en zonder beperkte schouderbeweeglijkheid.

In **hoofdstuk 6** hebben we de resultaten beschreven van de studie waarin bij 138 personen (deelnemers aan het Koepel- en SPIQUE project) met een dwarslaesie de associatie tussen schouderpijn en beperkingen van schouderbeweeglijkheid bij ontslag uit klinische revalidatie en activiteiten en participatie vijf jaar later onderzocht. De uitkomstmaten in deze studie waren maximaal inspanningsvermogen, rolstoelvaardigheden, FIM-Motor Score, mogelijkheid tot het zelfstandig uitvoeren van een transfer, PASIPD, mobiliteit en de sociaal gedrag subschalen van de Sickness Impact Profile 68 (SIPSOC) en werkstatus vijf jaar na ontslag.

We vonden in een bivariate analyse dat een beperking van de schouderbeweeglijkheid bij ontslag uit de klinische revalidatie gerelateerd was aan vrijwel alle uitkomstmaten. Dit gold niet voor schouderpijn. Echter, na correctie voor confounders (persoons- en laesiekenmerken en duur van de dwarslaesie) bleken personen met een beperking van de schouderbeweeglijkheid bij ontslag vijf jaar later minder vaak zelfstandig een transfer te kunnen maken, een lagere FIM-Motor Score te hebben en minder vaak te werken. In de multivariate analyse werd geen associatie meer gevonden met maximaal inspanningsvermogen, tijd nodig voor uitvoeren van taken van de rolstoelvaardigheidentest, de PASIPD en de SIPSOC.

In **hoofdstuk 7** hebben we de belangrijkste resultaten samengevat en bespraken we deze resultaten in de context van de huidige literatuur. Vervolgens hebben we een aantal methodologische aspecten bediscussieerd van het studiedesign van het Koepelproject en het

SPIQUE project en de relevantie daarvan voor de interpretatie van de resultaten. Gebaseerd op onze resultaten, de literatuur en onze expertise hebben we een aantal aanbevelingen voor vervolgonderzoek gegeven. We hebben voorgesteld om in vervolgonderzoek een meer alomvattende benadering van schouderproblemen toe te passen, inclusief kinematische analyse en radiologisch onderzoek. Verder hebben we voor het toepassen van uniforme uitkomstmaten in onderzoek gepleit en werd de rol en inhoud van mogelijk interventie-onderzoek besproken.

Tenslotte werd een aantal aanbevelingen voor de klinische praktijk gegeven. In de acute fase na een dwarslaesie moet een optimale positionering en vroege mobilisatie van het schoudercomplex gewaarborgd zijn. Training van de bovenste extremiteiten en hoe deze te gebruiken in de dagelijkse praktijk zonder risico op overbelasting, moet een belangrijke focus zijn tijdens de gehele revalidatie. Personen met een dwarslaesie (en revalidatieteams) moeten zich bewust zijn (of gemaakt worden) dat het in stand houden van een goede conditie van de bovenste extremiteiten een levenslange opgave is. Een optimaal passende rolstoel, naar de individuele eigenschappen van de gebruiker, inclusief type banden en bandendruk, moet voor elke persoon gegarandeerd zijn. Een alternatief voor de rolstoel, zoals de handbike, moet bij elke patiënt overwogen worden. Indien nodig moeten hulpmiddelen, met name voor transfers en voor het verplaatsen van de rolstoel in de auto, aangevraagd, goedgekeurd en toegepast worden. We adviseren een levenslange controle van de schouder in de (jaarlijkse) check-up als vast onderdeel in te voeren. Deze controle moet bestaan uit het (actief) vragen naar en het meten van schouderklachten, schouderbeweeglijkheid, een manueel schouderonderzoek, een analyse van rolstoelvaardigheden en transfers, een kinematische analyse van rolstoelvoortbeweging, een beoordeling van de huidige hulpmiddelen en eventueel benodigde nieuwe hulpmiddelen, alsook radiodiagnostiek van de schouder. Deze alomvattende manier van controle moet vroeg na de dwarslaesie beginnen en regelmatig over de tijd worden herhaald. Hierdoor kunnen schouderproblemen in een zo vroeg stadium worden gesignaleerd en kunnen de nodige interventies vroegtijdig worden toegepast om op deze manier blijvende schouderproblemen te voorkomen en zodoende bij te dragen aan het gezond ouder worden van personen met een dwarslaesie.

ZUSAMMENFASSUNG

“Die Herausforderung ist gesundes Altern, älter werden auf gesunde und aktive Weise. Die Aufrechterhaltung der Gesundheit über das Pensionsalter hinaus steigert die Lebensqualität, das Wohlbefinden sowie die Erwerbsteilnahme, die familiäre Unterstützung und andere signifikante Beiträge in der Gesellschaft. Neues Wissen zum Einfluss dieser Faktoren und wie sie miteinander interagieren, ist erforderlich.”

(Übersetzung Zitat: Healthy Ageing Campus Netherlands at <http://www.healthyageingcampus.nl/about/healthy-ageing>)

Das Thema dieser Dissertation ist eines der vorherrschenden Gesundheitsprobleme bei Personen mit einer Querschnittlähmung, nämlich Schulterschmerzen, die Einschränkungen des Bewegungsumfangs der Schulter und die daraus resultierenden Konsequenzen für Aktivitäten und Teilhabe.

Eine Querschnittlähmung resultiert in Muskelschwäche oder -lähmung, Sensibilitätsausfall und Ausfall der autonomen Funktionen unterhalb der Lähmungshöhe. Nach einer Querschnittlähmung brauchen ca. 80% aller Personen einen Rollstuhl und sind für die Fortbewegung und die Alltagsaktivitäten auf die oberen Extremitäten angewiesen. Somit ist es nicht erstaunlich, dass bei Personen mit einer Querschnittlähmung Schulterschmerzen und Einschränkungen im Bewegungsumfang der Schulter häufig vorkommen. Während der akuten und chronischen Phase der Querschnittlähmung beträgt die Prävalenz von Schulterschmerzen ungefähr 50%. Die Prävalenz von Einschränkungen des Bewegungsumfangs liegt während dem selben Zeitraum zwischen 30% und 40%. Obwohl angenommen wird, dass Schulterprobleme Aktivitäten, Teilhabe und somit die Lebensqualität negativ beeinflussen könnten, wurde der Zusammenhang zwischen Einschränkungen des Schulterbewegungsumfangs und Schulterschmerzen und Aktivitäten und Teilhabe noch wenig untersucht und die bisherigen Studien zeigten widersprüchliche Resultate. Somit war zu Beginn der Studie der Mechanismus der Entstehung von Schulterproblemen und deren Verlauf unklar.

Um Zielsetzung und Massnahmen in stationären und ambulanter Rehabilitation und Nachbehandlung zu optimieren, war das Ziel dieser Studie: 1) ein besseres Verständnis von Strukturänderungen, Prävalenz und zeitlichem Verlauf von Schulterproblemen (Schmerzen, Bewegungsumfang) zu bekommen, 2) die komplexen Beziehungen zwischen Schulterstruktur, Schulterfunktion und Aktivitäten und Teilhabe mit Hilfe der Internationalen Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit zu studieren.

Im **ersten Kapitel** wurde eine Übersicht über den Kontext der Dissertation gegeben. Eine kurze Beschreibung des Krankheitsbildes und der Epidemiologie der Querschnittlähmung wurde präsentiert. Weiter wurde eine Übersicht über die wichtigsten Begleit- und Folgeerkrankungen bei Personen mit einer Querschnittlähmung gegeben. Als dritter Punkt wurden die Konsequenzen einer Querschnittlähmung auf die Funktionsfähigkeit anhand des bio-psycho-sozialen Modells der Internationalen Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit erklärt. Folgend wurde die funktionelle Anatomie des Schulterkomplexes, das aktuelle Wissen über Schulterbeeinträchtigung bei Personen mit einer Querschnittlähmung und der Zusammenhang von Schulterschmerzen und Einschränkung des Schulterbewegungsumfanges mit Aktivitäten und Teilhabe beschrieben. Nach einer kurzen Beschreibung der medizinischen Versorgung und der Rehabilitation in den Niederlanden und der Schweiz, wurde der Forschungskontext aufgezeigt. Dieser beinhaltet die niederländische prospektive Kohortenstudie 'Restoration of mobility in spinal cord injury rehabilitation', auch bekannt als 'the Umbrella Project', und deren Nachfolgestudie 'Spinal Cord Injury Quality of Evaluation (SPIQUE)' der Schweizer Paraplegiker Forschung und des Schweizer Paraplegiker Zentrums. Zum Abschluss wurde ein detaillierter Überblick über das Ziel und die Forschungsfragen der vorliegenden Dissertation gegeben.

Körperstrukturen: Das Akromioklavikulargelenk

In **Kapitel 2** präsentierten wir eine Studie, die an der Schweizer Paraplegiker Forschung und dem Schweizer Paraplegiker Zentrum durchgeführt wurde. In dieser Studie verglichen wir die Prävalenz, den Schweregrad und das Risiko für eine Akromioklavikulargelenk-Arthrose in Personen mit Schulterschmerzen, entweder mit und ohne Querschnittlähmung.

Dazu führten wir eine retrospektive Analyse der Krankenakte von Personen mit Schulterschmerzen (68 Personen mit einer Querschnittlähmung und 105 Personen ohne Querschnittlähmung) durch und werteten die Magnetresonanztomographien aus, die im orthopädischen Ambulatorium gemacht wurden. Wir fanden heraus, dass die Gesamtprävalenz der akromioklavikulären Gelenksarthrose 98% für Personen mit einer Querschnittlähmung und 92% für Personen ohne Querschnittlähmung beträgt. In beiden Gruppen wurde die akromioklavikuläre Gelenksarthrose häufig von einer Ruptur der Rotatorenmanschette und der Bizepssehne begleitet. Die Sensitivität des klinischen Tests war tief bei den Personen mit einer Querschnittlähmung (0.31) sowie auch bei Personen ohne Querschnittlähmung (0.23). Die Wahrscheinlichkeit eines höheren Schweregrades der Arthrose war bei Personen mit einer Querschnittlähmung fast 4mal höher, als bei

Personen ohne Querschnittslähmung ($p < 0.001$). Nachdem die Effekte von Geschlecht und Alter kontrolliert wurden, zeigte die Analyse des Schweregrades der Arthrose bei Personen mit einer Querschnittslähmung eine schwache Assoziation mit der Zeitdauer seit Eintritt der Querschnittslähmung und keine Assoziation mit der Höhe oder Vollständigkeit der Läsion.

Wir folgerten daraus, dass Personen mit einer Querschnittslähmung und Schulterschmerzen eine gleiche Prävalenz für Akromioklavikulargelenk-Arthrose haben, aber sich in einem fortgeschrittenerem Stadium befinden, als Personen mit Schulterschmerzen und ohne Querschnittslähmung. Dies wurde sehr wahrscheinlich durch die hohe Belastung der Schulter durch das Rollstuhlfahren oder andere rollstuhlbezogene Aktivitäten wie Transfers und Gewichtsentlastung verursacht. Da eine frühe Diagnose der Arthrose eine Grundvoraussetzung für eine erfolgreiche konservative Behandlung der Schulterschädigung ist, empfehlen wir eine Routineuntersuchung des Schulterstatus, inklusive diagnostischer Bildgebung bei der jährlichen Untersuchung.

Körperfunktionen: Schulterschmerzen

Obwohl Schulterschmerzen einem Grossteil der Personen mit einer Querschnittslähmung Probleme bereitet, gibt es bis jetzt keine Studien, die den Langzeitverlauf von muskuloskeletalen Schulterschmerzen nach einer Querschnittslähmung empirisch untersucht haben. Deshalb waren die Ziele vom **dritten Kapitel**: 1) die spezifischen Verläufe von muskuloskeletalen Schulterschmerzen bei Personen mit einer Querschnittslähmung zu identifizieren, und 2) mögliche Prädiktoren für diese Verläufe zu bestimmen.

Wir untersuchten eine prospektive, multizentrische Kohorte bestehend aus 225 frisch verletzten Personen mit einer Querschnittslähmung in den Niederlanden (Teilnehmer der Umbrella und SPIQUE Studien). Die Schulterschmerzen wurden zu fünf Zeitpunkten erfasst: beim Start der aktiven Rehabilitation, drei Monate nach dem Start, bei Austritt aus der aktiven Rehabilitation, ein und fünf Jahre nach dem Austritt. Um die spezifischen Verläufe von Schulterschmerzen zu identifizieren wurde das 'latent class growth mixture modeling' benutzt.

Wir identifizierten drei unterschiedliche Verläufe von Schulterschmerzen: 'keine oder wenig Schmerzen' (64%), 'starke Schmerzen' (30%) und 'Abnahme der Schmerzen' (6%). Im Vergleich zum Verlauf 'keine oder wenig Schmerzen' umfasste der Verlauf 'starke Schmerzen' mehr Personen mit einer Tetraplegie, mit Schulterschmerzen vor der Querschnittslähmung, eingeschränktem Bewegungsumfang der Schulter, einem tieferen Wert beim manuellen Muskeltest oder mehr Spastizität zu Beginn der aktiven Rehabilitation. Die multivariate

logistische Regressionanalyse zeigte zwei signifikante Prädiktoren für den Verlauf 'starke Schmerzen' (im Vergleich zum Verlauf 'keine oder wenig Schmerzen'): Tetraplegie (odds ratio (OR)=3.2; $p=0.002$) und eingeschränkter Bewegungsumfang der Schulter (OR=2.8, $p=0.007$). Erstaunlicherweise fanden wir keinen Verlauf mit zunehmenden Schmerzen. Einer der Gründe könnte sein, dass eine Zunahme der Schmerzen aufgrund von degenerativen Erscheinungen erst mit zunehmendem Alter oder längerer Zeit seit der Querschnittlähmung auftritt. Deshalb wäre es sinnvoll, eine Studie mit einem späteren Messzeitpunkt zu machen.

Körperfunktionen: Bewegungsumfang der Schulter

Bis jetzt gibt es wenig Studien über die Prävalenz und die Veränderungen des Schulterbewegungsumfangs über Zeit. Deshalb untersuchten wir diese Faktoren bei Personen mit einer Querschnittlähmung und analysierten die Beziehung zwischen Einschränkungen des Bewegungsumfangs der Schulter und persönlichen und läsionsbezogenen Eigenschaften. Die Resultate dieser Studie wurden in **Kapitel 4** vorgestellt.

Es wurden 199 Teilnehmer mit einer neuen Querschnittlähmung in die niederländische Multicenter Umbrella-Studie eingeschlossen. Wir haben den Bewegungsumfang der Schulter beim Start der aktiven Rehabilitation, drei Monate nach dem Start, bei Austritt aus der aktiven Rehabilitation und ein Jahr nach dem Austritt gemessen. Wir fanden einen eingeschränkten Bewegungsumfang ($\geq 10^\circ$) bei bis zu 70% (95% CI: 57–81) bei Personen mit einer Tetraplegie, und in 29% (95% CI: 20–38) bei Personen mit einer Paraplegie während oder im ersten Jahr nach der stationären Rehabilitation. Die Schulterflexion war am meisten von Einschränkungen betroffen. Bis zu 26% (95% CI: 20–37) der Teilnehmer waren an beiden Schultern von Einschränkungen des Bewegungsumfangs betroffen. Wir sahen, dass Einschränkungen im Bewegungsumfang der Schultern häufig nach einer Querschnittlähmung vorkommen. Das Risiko für diese Einschränkungen ist höher bei einer Tetraplegie, mit höherem Alter, bei Spastizität des Ellbogenstreckers, bei einer längerer Dauer zwischen Verletzung und Beginn der aktiven Rehabilitation und bei bestehenden Schulterschmerzen.

Aktivitäten und Teilhabe: Assoziation mit dem Bewegungsumfang und Schmerzen der Schulter

Im **fünften Kapitel** haben wir die Resultate der Studie beschrieben, die den Zusammenhang zwischen Einschränkungen des Schulter-Bewegungsumfangs bei Austritt (bei 146 Teilnehmern mit einer Querschnittlähmung) und der Durchführung von Aktivitäten wie

Rollstuhlfahren und Transfers und Teilhabe ein Jahr nach dem Austritt untersuchte. Wir massen den Bewegungsumfang der Schulter bei Austritt aus der ersten Rehabilitation und bestimmten den Functional Independence Measure (FIM)-Motor Score, die Fähigkeit einen Transfer durchzuführen, den Wheelchair Skills Test (WST) und den Physical Activity Scale for Individuals with Disabilities (PASIPD) ein Jahr später. Mögliche Störfaktoren waren Alter, Geschlecht, Höhe und Vollständigkeit der Läsion, Zeitdauer seit Eintritt der Querschnittlähmung und Schulterschmerzen. Die Daten wurden für die ganze Gruppe (Paraplegie und Tetraplegie) und die Untergruppe Tetraplegie ausgewertet.

Wir sahen, dass die Teilnehmer, welche bei Austritt einen eingeschränkten Schulter-Bewegungsumfang hatten, ein Jahr später mehr eingeschränkte Selbständigkeit (FIM-Motor score) hatten, und dass Wahrscheinlichkeit für die unabhängige Durchführung eines Transfer kleiner war (ganze Gruppe fünf Mal kleiner, Personen mit einer Tetraplegie zehn Mal kleiner). Im Hinblick auf die Gesamtgruppe brauchten die Teilnehmer mit einem eingeschränkten Schulterbewegungsumfang mehr Zeit, um 15 Meter und eine liegende Acht im Rollstuhl zu fahren. In beiden Gruppen fanden wir keinen Zusammenhang mit dem Niveau der körperlichen Aktivität (PASIPD).

In **Kapitel 6** präsentierten wir die Resultate jener Studie, welche die Assoziationen zwischen Schulterschmerzen und Einschränkungen im Schulterbewegungsumfang bei Austritt der Erstrehabilitation mit Aktivitäten und Teilhabe fünf Jahre später untersuchte. Diese Analyse wurde bei 138 Teilnehmern der Umbrella- und SPIQUE-Studien durchgeführt. Die wichtigsten Messgrössen dieser Studie waren Spitzenleistung (POpeak) WST, FIM-Motor score, die Fähigkeit, einen Transfer durchzuführen, Mobility Range and Social Behavior scales of the Sickness Impact Profile 68 (SIPSOC) und Arbeitsstatus. Wir sahen, dass nur die Einschränkungen im Bewegungsumfang der Schulter bivariat mit allen, ausser einer Messgrösse assoziiert sind. Nachdem für Störfaktoren korrigiert wurde (persönliche und läsionsbezogene Eigenschaften) zeigte sich, dass Einschränkungen im Schulterbewegungsumfang bei Austritt negativ mit der Fähigkeit einen Transfer durchzuführen, dem FIM-Motor Score und der Rückkehr zur Arbeit assoziiert waren. Wir fanden keine Assoziationen zu POpeak, Zeit der WST, dem PASIPD und SIPSOC.

Im **siebten Kapitel** wurden die wichtigsten Ergebnisse zusammengefasst und im Kontext der wissenschaftlichen Veröffentlichungen diskutiert. Anschliessend diskutierten wir einige methodologische Überlegungen in Bezug auf das Studiendesign und deren Auswirkungen auf die Interpretation und die Verallgemeinerbarkeit der Resultate. Basierend auf unseren Resultaten, der verfügbaren Literatur und klinischer Erfahrung gaben wir Empfehlungen

für zukünftige Forschung, wie zum Beispiel die Durchführung von Studien mit einem umfassenden Ansatz, welche Bewegungsanalysen und diagnostische Bildgebung enthalten und einheitliche Messgrößen verwenden. Zusätzlich diskutierten wir die Rolle und den Inhalt von möglichen Interventionsstudien.

Zum Schluss beschrieben wir einige Empfehlungen für die klinische Praxis. Während der akuten Phase sollte die optimale Positionierung der Schulter und die frühe (passive oder aktive) Mobilisation des Schultergelenks gewährleistet sein. Während der Rehabilitation sollte das Training der oberen Extremitäten und der richtige Gebrauch der Schulter während des Trainings im Fokus stehen. Den Patienten sollte bewusst sein, dass das Training der oberen Extremitäten eine lebenslange Aufgabe ist und ihnen sollte gezeigt werden, wie sie ihre Schultern am besten trainieren und im Alltag einsetzen, so dass Überlastungsverletzungen der Schulter vermieden werden. Zusätzlich sollte bei jedem Patient mit einer Querschnittlähmung gewährleistet sein, dass der optimale Rollstuhl gewählt wird, der an die individuellen Bedürfnisse angepasst ist, wobei eine optimale Ergonomie, Mechanik, Reifentyp und Reifendruck beachtet werden soll. Ein zusätzliches Fortbewegungsmittel welches für die Schultern weniger belastend ist, wie zum Beispiel ein Handbike, sollte für jeden Patienten in Erwägung gezogen werden. Falls erforderlich sollten Hilfsmittel für den Transfer eingesetzt werden und Anpassungen des Autos vorgenommen werden, um dem Rollstuhl zu verladen und transportieren. Wir empfehlen, umfassende und lebenslange Nachfolgeuntersuchungen von Schulterproblemen bei Personen mit einer Querschnittlähmung einzuführen. Diese Untersuchungen sollten einerseits medizinische Anamnesen, klinische Untersuchungen und diagnostische Bildgebung beinhalten, und andererseits sollten Beobachtungen, kinematische Analysen des Rollstuhlfahrens, Rollstuhlfertigkeiten und die Erfassung von Nutzen und Bedürfnis von Hilfsmitteln gemacht werden. Diese umfassende Beurteilung der Schulterfunktion zu einem frühen Zeitpunkt nach der Querschnittlähmung und während des weiteren Lebens ist wichtig, um Schulterprobleme früh zu diagnostizieren und erfolgreich zu behandeln, damit gesund altern so gut wie möglich gewährleistet ist.

Dank (m): (betuiging van) goede gezindheid tegenover iem. vanwege een geschenk, bewezen dienst.

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Inge Eriks-Hoogland was born on August 10th 1970 as the daughter of Jan Eriks and Ria Eriks-Tiebie in the 'Zuidelijke IJsselmeerpolders', the Netherlands. She studied Medicine at the Vrije Universiteit in Amsterdam. During a 3 weeks project on 'Cooperation and communication between health departments', she visited the spinal cord department

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In 2006 she moved to Switzerland and started working as Medical Officer of the Swiss Paraplegic Research on the development and implementation of the multicenter Swiss Spinal Cord Injury Cohort Study (SwiSCI) and works as PM&R physician at the Swiss Paraplegic Centre. During the last years Inge participated in several publications (see 'Publications') and is a reviewer for several scientific journals.

Inge lives in Buttisholz, is married to Frank Hoogland, and the mother of three girls, Emma (2004), Julie (2007), and Sarah (2010).

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